

**EXPERIENCES OF PARENTS WHOSE CHILDREN WITH AUTISM
SPECTRUM DISORDER (ASD) ARE STARTING PRIMARY SCHOOL**

MICAELA CONNOLLY

**A thesis submitted in partial fulfilment of the requirements
of the University of East London
for the degree of
Doctor of Applied Educational and Child Psychology**

January 2015

Abstract

The transition to school is considered a key event in a child's life. It is also a major event in their parents' lives. Children with autism spectrum disorder (ASD) are considered to be particularly vulnerable in the transition process because of their difficulties with social communication, social interaction and change. Transition programmes that facilitate the child in starting school naturally focus on the child's needs but a review of the literature revealed little research into the experiences of parents whose children with ASD were starting school. In this study, a qualitative method, Interpretative Phenomenological Analysis (IPA), was used to explore the perceptions and experiences of parents whose young children with ASD were starting school in September 2013. Interviews with six participants were transcribed and analysed and examined individually. A cross-case analysis revealed three common overarching themes which reflected their experiences of the transition process and their interactions with other people in the child's life. These include 'I think they need to believe, *believe* what we're telling them', 'Experience of ASD: It's a very labelling thing' and 'Preparing for school and feelings about the future'. Key findings which add to the literature on this under-researched topic are described and implications are discussed with particular reference to the role of the educational psychologist in facilitating optimal outcomes for parents of children with ASD in the transition process.

Student Declaration

This work has not been accepted for any degree and it is not currently being submitted for any other degrees.

This research is being submitted in partial fulfilment of the requirements of the University of East London for the degree of Doctor of Applied Educational and Child Psychology.

The thesis is the result of my own work unless otherwise stated. Other sources are acknowledged by explicit references in the text. A full reference list is included in the appendices.

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File size: **15.62M**
Page count: **305**
Word count: **88,797**
Character count: **476,761**
Submission date: **12-Jan-2015 08:45PM**
Submission ID: **39498127**

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List of abbreviations

AS	Asperger's syndrome
ASC	Autism spectrum condition
ASD	Autism spectrum disorder
DD	Developmental disability
DES	Department of Education and Skills
DoH	Department of Health
HT	Home tutor
ID	Intellectual disability
IPA	Interpretative Phenomenological Analysis
LA	Local authority
MDT	Multidisciplinary therapeutic team
NCSE	National Council for Special Education
NICE	National Institute for Health and Care Excellence
SEN	Special Educational Needs
SENO	Special Education Needs Organiser
SNA	Special Needs Assistant

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Acknowledgements

This thesis is dedicated to the memory of my father who is my inspiration. I know he would be “enormously proud” of me.

I would like to express my gratitude and appreciation to the parents who took part in this study. Without their courage, honesty, eagerness to help others, and generosity, this exploration would not have been possible. I hope I have done their stories justice.

I would like to thank my husband, Anthony, and my children, Jack and Luke, for their patience and encouragement through every step of this process. Without their support and forbearance, I could not have completed this project. Gratitude and thanks are also due to my mother, my family and friends for believing in me and encouraging me.

I would like to sincerely thank my supervisors and teachers at UEL, Irvine and Sharon. I am greatly appreciative of their encouragement and support. I have been inspired by them and feel privileged to have benefitted from their wealth of expertise, wisdom, and knowledge.

Thanks are due to my fellow students at UEL, for their generosity and advice, which made the process so much easier.

I would like to thank my friends and work colleagues at the Brothers of Charity for all their help and support and encouragement through the whole process. To Catherine, who got me into this; to Helen, Charlotte, Mary, my manager, and the Brothers of Charity management who supported and facilitated this research project. To my friends Geraldine, Catherine, and Robbie who led the way.

“Answers do not matter so much as questions, said the Good Fairy. A good question is very hard to answer. The better the question the harder the answer. There is no answer at all to a very good question.”
(Flann O’Brien, *At Swim-Two-Birds*)

1 INTRODUCTION

1.1 Overview of Chapter One

This study aims to explore the experiences of parents whose children with autism spectrum disorder (ASD) are starting primary school. Starting school is considered a critical event in a child's development and successful transitions to school have been posited as key indicators for future academic achievement. For children with autism spectrum disorder (ASD), the process is complicated by the difficulties in social communication and social interaction that characterise the condition. Parents of children with ASD can experience their child's transition to school as a stressful time. Despite their key role in the transition process, little research has been conducted into parents' perceptions and experiences. This study contributes to the literature on transitions to primary school for children with ASD by examining the process from the parents' point of view; acknowledging and understanding parents' perspectives may help professionals in making the transition process more positive for parents and may assist in ensuring smoother transitions for children with ASD.

I will report the study in the first person given the nature of the method and my role in the investigation. In Ireland, ASD is variously referred to as autism spectrum disorder and autistic spectrum disorder. I am aware that the term autistic spectrum condition (ASC) is in use in the UK, as described in the Autism Act (2009). The term autism spectrum disorder (ASD) is used throughout this study as this is the term used by the Psychological Society of Ireland's Autism Spectrum Disorders Special Interest Group, in the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-V) (American Psychiatric Association, 2013) and frequently in the research literature. The terms autism and ASC are employed when discussing research papers where this terminology is used out of respect to the authors.

This thesis begins with Chapter One in which the topic under review is introduced, namely the experiences of parents whose children with autism spectrum disorder (ASD) are starting primary school. In section 1.2, the

research aims and research questions in this study are presented. The rationale and justification for the study are introduced in section 1.3. This includes a discussion of the background and context of the study, the genesis of the research and my involvement in the area. In section 1.4, an overview of ASD and the conceptualisation of disabilities in Ireland are presented. Section 1.5 describes the context of educational provision for children in Ireland with particular reference to children with ASD. In section 1.6, an outline of the theoretical links underpinning the study is presented. The distinctive contribution that this study makes to knowledge and understanding of the experiences of parents who are sending their young children with ASD to school is discussed in section 1.7. The final section, 1.8, summarises this chapter.

Chapter Two includes a review of the literature relating to the topic under examination in this study. I conducted the literature review in two phases. The first phase was carried out prior to the data collection in order to identify key literature around the topic. The second phase involved a critical review of the relevant research. These are presented in Chapter Two. This chapter also provides a discussion of the theoretical framework underpinning the research.

Chapter Three presents the methodology used in the study, the rationale behind my choice of research method, and how it related to the research questions. The method chosen was a qualitative research method, Interpretative Phenomenological Analysis (IPA), as I considered it the most appropriate method for addressing the research questions. In this study, I examined six cases individually, in line with IPA's idiographic stance, and then performed a cross-case analysis. My role in analysis is made explicit in the 'double hermeneutic' process, where I describe the interpretation and analysis of the participant's interpretation of the phenomena under examination. I implemented a reflexive process across all stages of the study and this is detailed in Chapter Three. Issues relating to quality and rigour in the research process are also discussed.

The findings from the cross-case analysis of the interviews in the study are presented in Chapter Four. Chapter Four outlines the identification and analysis of common themes relating to participants' experiences of their children with ASD starting school, with particular attention to their meaning-

making and perceptions; the hermeneutic aspect of the process is described in detail.

Chapter Five presents a discussion of the findings and their relationship to the research literature. The study is critiqued and its distinctive contribution to the research literature is discussed. Topics meriting further investigation are introduced. Chapter Five also presents implications for EP practice in addition to conclusions from the study.

The appendices include additional information on topics discussed in the main text, evidence of ethical approval, consent forms, a sample of raw data from the transcripts, a sample of an individual findings chapter and evidence of the development of themes. The following section describes the research aim in the study.

1.2 Research aim

The principal aim of this research is to add to findings on the experiences of parents of children with ASD, with particular reference to their children's transitions from preschool to primary school. I posed the following research questions:

- What are the experiences of parents whose children with ASD are starting school?
- What goals and options do parents feel they have around their children's education?
- What kinds of feelings do parents have around their children starting school?

A desirable outcome of the study was that gaining greater knowledge of the unique perceptions of this group of people would lead to enhanced understanding and improved service delivery to parents of young children with ASD.

1.3 Rationale and justification for the study

According to Dockett and Perry (2007), human development could be conceived as a series of transitions which are described both in terms of events, such as a child starting school, and in broader social and cultural terms, such as a child taking on the role of 'school child' in their community. A review of the literature on transitions to primary school revealed a substantial body of research into the child's perspective in the transition process as it has been posited as a major event in any child's life (Fabian & Dunlop, 2007) and a "critical period" for the child's academic and social achievement which has implications for their future achievement (Entwisle & Alexander, 1993, p. 404).

The start of school can also be perceived as a time of transition for parents (Dockett, Perry, & Kearney, 2012). Reference has been made in the literature to the family as the principal context in which the child's development takes place (Bronfenbrenner, 1986) and family members were viewed as partners in the process of facilitating the child's transition to school (Stoner, Angell, House, & Jones Bock, 2007). Family characteristics have been examined to explore the influence of the family context on the child's adaptation to primary school (Cowan, Cowan, Ablow, Johnson, & Measelle, 2013) but the actual experience of parents around the process of the child starting school has received little attention in the research literature, despite calls to do so; researchers such as Rimm-Kaufmann and Pianta (2000) have identified a need for research into the factors that contribute to family-school interactions and explain how family-school relationships can be cultivated.

Studies that have investigated the experiences of parents of children with ASD in choosing a school placement (see Cassidy, McConkey, Truesdale-Kennedy, and Slevin (2008) found a significant number, if not a majority, of participants in their study wanted to send their children to mainstream school but research on parents' experiences and perspectives in relation to children with ASD starting school is sparse (Stoner, Angell, House, & Jones Bock, 2007). This study addresses a gap in the literature and offers a detailed and timely exploration of parental experiences and perspectives around their children's transitions to school.

1.3.1 Background and context to study

In this section, the background and context in which the current study took place will be described. Individuals with ASD present with significant social and other difficulties which will be outlined in detail in section 1.4. Due to the pervasive nature of these difficulties, the condition is seen as a disability in Ireland, as is the case in many developed countries. Children with ASD receive support from multidisciplinary therapeutic teams (MDTs) which include occupational therapists, social workers, psychologists, speech and language therapists, and physiotherapists. This support is provided by the Department of Health (DoH) directly, or through voluntary agencies. The present study took place in one such voluntary agency. I work as an educational psychologist (EP) on a team providing multidisciplinary assessment and therapy to children with ASD. Part of my work involves supporting children who are starting primary school and their families. This can include observation and assessment of children's functioning in preschool, identification of areas of need for primary school, provision of support for parents in choosing school placements, provision of written documentation to support applications for resources in school, provision of training for primary school staff around strategies to support children with ASD in the school setting, and provision of support to children, parents and primary school staff when the children start school.

The participants came from two counties in the south of Ireland. They comprised six parents whose five children attended one of four different voluntary agencies providing MDT services for children with a diagnosis of ASD. The children were all five years of age and were due to start school the following September.

In the next section, my involvement in the area and the genesis of the research is discussed.

1.3.2 Genesis of the research and my interest in the area

In my work as an EP, I am involved in providing support around transition to primary school mentioned above. Each September, a number of children in the service start school. While parents are included in aspects of the transition process, such as sharing information about their children with members of the MDT, I have noted a lack of real and meaningful consultation with parents

around their views and experiences of the transition process. Therefore, I do not really know what the experience is like for parents. Previous research into parents' experiences of waiting for a diagnostic assessment for ASD for their children asked parents directly about their feelings and perspectives and gave practitioners valuable insights into their unique experiences (Connolly & Gersch, 2013).

In the present research I was interested in finding out what it's like for parents whose children with ASD are starting school to see if their perspectives could be included in the transition process and to see if there was **support** they needed that the MDT could provide.

In the next section, an outline of ASD is provided to give insight into the condition and the complexity of the issues involved.

1.4 Autism Spectrum Disorder

ASD is a complex, pervasive neurodevelopmental disorder which is typified by persistent deficits in social communication and social interaction in the presence of stereotypical and repetitive behaviours (American Psychiatric Association, 2013). First described by Kanner as autistic disturbances of affective contact (Kanner, 1943), autism was originally viewed as a constitutional disorder most likely arising from inborn errors of metabolism. The year after Kanner published his 1943 paper, and apparently independently, Asperger described a disorder of autistic psychopathy, now known as Asperger's Syndrome (AS). These two disorders have been viewed as similar but distinct facets of the autism spectrum and are the more common of the conditions on the spectrum; three other disorders, Rett's Syndrome; Childhood Disintegrative Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) complete the autism spectrum (Matson & Wilkins, 2008).

ASD is conceptualised as a spectrum disorder in an attempt to capture the heterogeneity in the presentations of individuals with the disorder. The common symptoms which typify the spectrum are described as a 'triad of impairments' to reflect a cluster of distinctive deficits in three core areas; social communication, social interaction, and social imagination (Wing & Gould, 1979). In addition to these impairments, an individual may present with motor co-ordination difficulties (Fournier, Hass, Naik, Lodha, & Cauraugh, 2010); sensory

issues; emotional and behavioural issues (Maskey, Warnell, Parr, Le Couteur, & McConachie, 2013); issues with attention and impulsivity (Sturm, Fernell, & Gillberg, 2004); psychiatric disorders (Simonoff et al., 2008), and intellectual disability (ID). ASD is a lifelong condition and developmental outcomes are variable; while some adults with ASD achieve independence, many need lifelong support and care (Howlin, Goode, Hutton, & Rutter, 2004). A description of current knowledge on the aetiology, prevalence, and construction of ASD is presented below.

1.4.1 Aetiology, prevalence, and construction of ASD

There is a large and growing body of biomedical research into ASD, focusing on the aetiology of what some theorists refer to as the ‘autisms’ (Coleman & Gillberg, 2012), referring to the theory that ASD is best understood not as a single large spectrum of disease but as a “specific set of symptoms found in a conglomeration of different diseases” (p. xi).

ASD has been found to be highly heritable (Bailey et al., 1995) and research suggests multiple genetic causes that impact on the development and function of brain structures mediating cognition and language (Geschwind & Levitt, 2007). There is no clear evidence as to a single cause but recent advances in the understanding of genetic mechanisms seem to suggest that many distinct disorders such as schizophrenia; autism, and epilepsy, may have common underlying genetic mechanisms which support the view that certain neurological disorders may have a similar underlying nosology (Kim & State, 2014).

The prevalence of ASD has risen dramatically in recent years. Recent estimates suggest figures of 62 per 10,000 (Elsabbagh et al., 2012) to 157 per 10,000 (Baron-Cohen et al., 2009). In the following section, I will discuss issues relating to how ASD is construed within various theoretical frameworks.

1.4.2 Theoretical construction of ASD

In many ways the essential nature of ASD remains elusive. Fitzgerald (2012) outlines three ways in which researchers have tried to resolve the core construction of ASD; firstly, questioning whether ASD is a social or a biological

phenomenon, for example, trying to interpret whether the ‘epidemic’ of ASD reflects advances in diagnostic practice or an actual biological change in the population; secondly whether the discovery of ASD reflects a biological reality or a cultural and societal change in the way disorders of development are construed, and thirdly, whether ASD is a distinct cultural form as claimed by proponents of the neurodiversity movement. Neurodiversity is a concept promoted by some people with ASD and their advocates that emphasises difference rather than deficits in the neurological functioning of people with ASD; many people with ASD and AS argue that, though they may think differently to typical peers, they do not have a disorder.

In this complex theoretical territory, it is useful to review Morton and Frith’s (1995) causal model, which attempts to map a shared theoretical framework for autism between the environmental; biological; cognitive, and behavioural features of the disorder. **Figure 1.1** illustrates how this might be conceptualised.

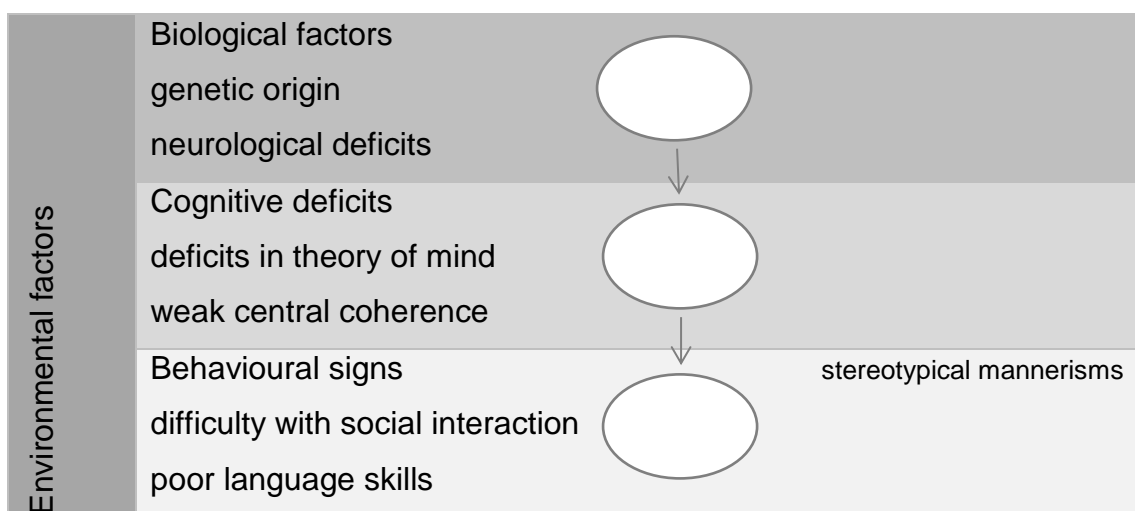


Figure 1.1 Causal model of ASD (after Morton and Frith, 1995)

In figure 1.1 above, ASD is conceptualised as the complex interplay between the biological underpinnings which shape the development of cognitive processes, resulting in observable behavioural features such as the stereotypical movements that some people with ASD make. The role of the environment is acknowledged through such factors as the construction of ASD

as a disability or a distinct cultural form, and through support that a child with ASD receives to ameliorate their difficulties.

Due to its complexity, ASD **has been** described within a number of theoretical frameworks. It has been researched extensively at a biological level including neuroscientific and genetic research (Geschwind & Levitt, 2007). At a cognitive level, constructs such as 'theory of mind' (TOM), the ability to conceive of mental states in others (Baron-Cohen, Leslie, & Frith, 1985) and 'weak coherence bias' (Happé & Frith, 2006), where people with ASD show a superiority in cognitive processing of object features at a local as opposed to global level, have been posited to try to explain differences in cognitive processing. At a behavioural level, poor skills in social communication and social interaction are core observed features which typify ASD (Wing, 1981).

1.4.2.1 Biomedical construction of ASD

The construction of ASD as a biologically-based developmental disorder has led to a focus on the search for a treatment and cure as evidenced by the United States Combating Autism Act (US Congress, 2006). Biomedical treatments that promise to alleviate symptoms or cure the disorder have proliferated in recent years. E. Hanson et al. (2007) found that many parents of children with ASD used complementary and alternative therapies with their children, including modified diets (gluten-free and casein-free for example); vitamin therapy, and food supplements despite the questionable efficacy of these treatments (James, Montgomery, & Williams, 2011; Millward, Ferriter, Calver, & Connell-Jones, 2008; Nye & Brice, 2005).

Given that ASD has been conceptualised variously as a developmental; neurodevelopmental (Rosenfeld et al., 2010), and a neuropsychiatric condition (Abrahams & Geschwind, 2010), it is notable that diagnosis continues to be based solely on symptomatology (Ecker, Spooren, & Murphy, 2013) where the core deficits described above are identified through behavioural observation; interview, and assessment.

1.4.2.2 Social construction of ASD

Another body of research has focused on the social construction of ASD. Commentators such as Nadesan (2005) viewed ASD as partly socially constructed for, though ASD has a biological basis, it is in many ways socially construed and conceptualised. McGuire (2012) construed ASD as a social identity category; in this view, ASD was seen through the lens of the social model in disability studies where the 'problem' of disability is located in society; it is not an individual's impairment that is the primary issue but society's failure to adequately address the individual's needs and provide appropriate support (Oliver, 1990). Kapp, Gillespie-Lynch, Sherman, and Hutman (2013, p. 10) described a deficit as difference model which supports the notion of "disability as an interaction between social factors and personal deficits, the challenges of which do not necessarily make life less valid or worthwhile but an equally valid part of human diversity". This position is that held by people in the neurodiversity movement.

1.4.3 Concept of disability in Ireland

In Ireland, ASD is viewed as a disability and this conceptualisation has impacted on governmental policies and strategies in relation to the kinds of provision that is made for individuals with ASD. The Disability Act (Government of Ireland, 2005) states that services should be provided which ameliorate a person's difficulties. The last two decades have seen a change in the way disability is conceived in Ireland and it is now more commonly recognised as a social, in addition to a medical, issue (Government of Ireland, 1996), emphasising that barriers to equal participation in typical life experiences are primarily social. At government level, there has been the promotion of a civil rights perspective in relation to equality of opportunity and inclusion in all aspects of society for people with disabilities. The state provides support for children with ASD which are described in the next section.

1.4.4 Support for children with ASD in the health domain

Parents of children with ASD receive state benefits; allowances, and tax reliefs to provide for the extra care and attention that the child with ASD needs. The

Health Service Executive (HSE), under the DoH, funds free health and community care services to children with disabilities, including ASD.

Therapeutic services are provided by the HSE directly in some regions, and via grant aid to voluntary sector agencies in others. These services include the provision of multidisciplinary diagnostic assessment and therapeutic intervention to children with a diagnosis of ASD. Multidisciplinary therapeutic teams (MDT) typically comprise psychology, speech and language therapy, social work and occupational therapy. Where necessary, respite and residential services are provided depending on the severity of a child's difficulties. In the next section, an outline of the context of educational support for children with ASD in preschool and primary school settings is presented.

1.5 Context of educational support for children with ASD

In this section, an overview of preschool provision and transition practices in Ireland is provided, the context of educational provision is outlined, and provision for children with ASD in the educational context is discussed.

1.5.1 Context of early childhood education and care in Ireland

Early education provision for young children is delivered by private, voluntary, and community providers in Ireland. The state gives a capitation grant to providers through the Early Childhood Care and Education (ECCE) Scheme which accords a free year of preschool education to children prior to starting school. A fundamental aim of the scheme is to benefit children in this key developmental period. A parliamentary report notes a 94% uptake of the scheme (Oireachtas Library Research Service, 2012).

1.5.2 Preschool provision for children with ASD

In the preschool period, the DES provides special educational provision to ameliorate the effects of ASD in what is considered a key developmental stage. Provision includes special preschools and special preschool classes attached to mainstream schools. The Department of Education and Skills (DES) provides a grant to parents of children with ASD of preschool age to allow the child to avail of home tuition, a scheme which aims to provide compensatory education for

children who are unable to attend school or for whom an appropriate school placement is not available. In the case of young children with ASD, the scheme aims to provide an individualised early educational intervention programme to children from two and a half years up to pre-school. A number of special preschools for children with ASD are funded by the DES and a new development in the provision of special preschool classes attached to mainstream schools has been underway in recent years. A search for information on these new classes revealed little by way of literature on policy or practice but the previous Minister for Education and Science had requested a review by the National Council for Special Education (NCSE) on policy advice on educational provision for students with ASD at the time of writing. The National Council for Special Education (NCSE) is the government agency with the remit to improve the delivery of education services to people with special educational needs (SEN).

In this study, one child had attended a special preschool service; one child had attended a special preschool and his local mainstream preschool, and the three other children had attended their local mainstream preschools. This was due to parental choice in four of the children's cases; in one child's case, her late diagnosis with ASD had led to her missing out on a suitable placement in a preschool for children with ASD because she was considered too old to enrol at the time of application.

1.5.3 Transition practices in Ireland

A review of transition practices in Ireland yielded little in the research relating to transition practices for children with ASD. Indeed, researchers have cited a dearth of information on transition practices for children in general in Ireland (O'Kane & Hayes, 2006).

In a study of teacher's perspectives on transitions to primary school, O'Kane and Hayes (2006) found that preschool teachers and teachers of junior infant classes held that the following general areas; social skills, independence, language and communication skills, and the ability to sit, listen and concentrate, were particularly important child characteristics for successful transitions. The teachers surveyed perceived that children at-risk of having a difficult transition were in the following categories; children with low self-esteem, those who had

difficulty concentrating, sitting still and listening, and those with behavioural problems. The next categories most frequently cited were children with no preschool experience and those with special needs. The most common transition practices noted in the study included a letter to parents before the start of school and arranging for parents and children to have one visit to school prior to starting. McGettigan and Gray (2012) found that transition practices varied in Ireland.

1.5.4 Primary school education in Ireland

The government of Ireland provides free primary education to all children in the Irish state. Article 42 of the Constitution of Ireland holds that the primary and natural educator of the child is the family, endowing parents with a fundamental role in their children's education. Children in Ireland begin compulsory school between the ages of four and six years of age, with a school start date around the first week in September each year. The reception year is called junior infants and, because of the flexibility around the age at which children can start school, children are generally of mixed ages.

The state does not oblige parents to send their children to particular schools and schools are not obliged to accept particular children. Nevertheless, in line with inclusive policies and legislation, such as the Equality Act (Government of Ireland, 2004), schools and other institutions in the education sector must observe principles of equality and adopt inclusive practices in as much as is practicable.

The NCSE appoints Special Educational Needs Organisers (SENOs) to identify the needs of children and the level of resources schools require to offer the most appropriate educational service to them. The role of the SENO bears some resemblance to that of the Special Educational Needs Co-ordinator (SENCO) in the UK.

1.5.5 *Support for children with ASD in education*

Children with ASD are viewed as having SEN due to the pervasive nature of their difficulties and have access, in theory, to a range of educational options which include full time participation in mainstream school settings, partial

inclusion in mainstream settings through attendance in special classes attached to mainstream schools, and partial or full-time attendance in special schools for children with ASD and/or ID. Guidelines for placement and resourcing are provided by DES circulars to schools, the recommendations contained in professional reports, and in accordance with parental wishes. In practice, a lack of suitable placements in special preschools, special schools and special classes can lead to waiting lists and children having to attend less than optimal educational placements.

Children are granted access to special needs assistants (SNA) in school to support them with specific needs. These are additional needs which relate to the category of their disability, their care needs (such as toileting and feeding) and medical needs, their level of physical or sensory impairment, or where the child's behaviour places themselves or other pupils at risk. These stipulations result in some children with ASD not qualifying for access to an SNA as they are deemed not to have significant needs. Children with ASD are automatically entitled to a **certain amount** of learning support teaching per week. Learning support provides extra tuition in school to support the child's educational achievement and progress there.

Once considered a low-prevalence disorder, ASD is currently one of the most common forms of developmental disability (Newschaffer et al., 2007) and is now seen as a primary disability condition. As a consequence, there has been a dramatic increase in the number of children with ASD attending mainstream schools and an increase in the number of special classes attached to mainstream schools for children with ASD. According to the NCSE, 54% of special classes in mainstream primary schools are designated for pupils with ASD (NCSE, 2010), a number which has been growing steadily. Despite this growth in provision, an absence of research into the impact of special classes on the student's outcomes and the extent to which inclusive practices are implemented has been noted (Parsons, Guldberg, et al., 2009).

In this study, two of the children were due to attend special classes attached to mainstream schools; three of the children were due to attend mainstream classes, one of them without access to an SNA.

1.6 Theoretical links

A review of the literature on children starting school comes within the theoretical construct of transitions, whereby the move to school is seen as both a continuous process and a “crucial event” (Sayers et al., 2012, p. 45).

Investigators have examined the topic of transition to school within a variety of theoretical frameworks including theories which focus on within-child characteristics such as the child’s readiness for starting school (Entwisle & Alexander, 1993), and which reflect a maturational, nativist theoretical stance (Carlton & Winsler, 1999); the nature of the transition process, for example, the experience as a rite of passage from an anthropological perspective (Fabian, 2000) leading to changes in identity, roles, and relationships (Griebel & Niesel, 1999). The readiness of the school system to cater for the child has also been explored (Dockett, Perry, & Kearney, 2010; Kagan & Rigby, 2003).

Theories that emphasise the ecological and chronological contexts of transitions (Bronfenbrenner & Morris, 2006; Rimm-Kaufman & Pianta, 2000) have become more widely cited in the literature. Among the most influential contextual models is the bioecological model of human development (Bronfenbrenner & Morris, 2006) which attempted to explain human development as situated within a temporal and environmental context. The four principle properties of the model were process, person, context, and time. A number of researchers have adopted Bronfenbrenner’s bioecological theory and used it as the basis for exploring the process of the child starting school. Rimm-Kaufmann and Pianta (2000) developed a model of kindergarten transition to school which took into account the influence of contexts, such as the family and the preschool, and the importance of relationships and connections between contexts over time. Rous, Hallam, Harbin, McCormick, and Jung (2005) developed a model for transitions that explored the ecological context and the transition process itself at two separate levels. Level One contained contextual factors such as broad social norms and features of the community, while Level Two contained specific information on the transition process including transition practices and outcomes for the child and family. This model attempted to parse out and examine relevant factors in the process. While these models referred to the role of the child and the family in the transition process, little reference was made to the parents’ experiences of the process.

In the present study, Bronfenbrenner's bioecological theory (Bronfenbrenner, 1994; Bronfenbrenner & Morris, 2006) was used as a theoretical underpinning, allowing the examination of "processes and conditions that govern the lifelong course of human development in the actual environments in which human beings live" (Bronfenbrenner, 1994, p. 37). This model allowed me to position the parent as a central figure within the transition process, facilitating a detailed analysis of their unique perspectives in the context of the process. Bronfenbrenner's theory is discussed in greater detail in Chapter Two. In the next section, the distinctive contribution of this study to the research literature is discussed.

1.7 Distinctive contribution of this research to knowledge

The research in this study builds on knowledge about parents' experiences of their children with ASD starting primary school. Despite the need for understanding and information around parental perceptions and experiences, a thorough review of the current literature revealed a paucity of knowledge around the feelings and concerns of parents of young children who are transitioning to school, including the perspectives of parents of young children with ASD. Knowing how parents feel about transitions is part of the process whereby professionals can develop necessary collaborative, family-centred practices (M. J. Hanson, 2005), and is an area which the current study addresses.

In this study, I analysed and interpreted parental experiences in detail. While the roles of parents in the transition process have been examined in the literature, parents' perceptions of the process have not been conceptualised at a theoretical level; this study examines the unique position and perceptions of parents of children with ASD in the transition process using the bioecological model as a theoretical framework. The findings are discussed in the context of the literature on transitions in Chapter Five.

1.8 Summary of Chapter One

Chapter One introduced the topic under examination in this study, namely the experiences of parents whose children with ASD are starting school. The aims of the study were described as was the rationale for conducting the research.

The transition to school is considered an important milestone in a child's life and parents are key people in the process. A review of the literature yielded a dearth of knowledge around parents' unique experiences of this event and so it was decided that this would be a worthy topic for research. Parents of children with ASD can experience stress around their children starting school, therefore finding ways of supporting and collaborating with them was of particular interest for me; I hoped that finding out more about parent's experiences would facilitate professionals in supporting parents and children as they prepare to start school.

The background and context to the study have been described in this chapter. The study took place in a voluntary organisation providing MDT services to children with ASD and their families. An overview of ASD and the conceptualisation of disability in Ireland were provided. This overview gave an insight into the complexity of the condition and the various ways in which it is conceptualised, from social to biomedical models. People with ASD form a heterogeneous group and, while there may be similarities in the core features of the condition, each child has a different presentation with different strengths and needs. This necessitates a spectrum of educational provision, from more supported and specialised settings to inclusion in mainstream schools. The context of educational provision in the preschool and primary school settings has been described, giving insight into the range of choices parents may, or in the case of limited resources, may not have for their child's education.

The distinctive contribution that this study makes to knowledge of parents' experiences of sending their children with ASD to primary school has been presented and will be discussed in more detail in Chapter Five. In Chapter One, theoretical models that underpin children's transitions to school were described, demonstrating the variety of perspectives around research into the topic. The model chosen to underpin the present study was Bronfenbrenner's bioecological model (Bronfenbrenner & Morris, 2006) as it provided a means of positioning parents in the transition process, allowing an exploration of their experiences. In the next chapter, this model is described in detail. Chapter Two also provides a detailed review of the research literature relating to the topic in this study. Relevant findings from the literature are introduced and critiqued in the following chapter.

2 REVIEW OF THE LITERATURE

2.1 Overview of Chapter Two

Chapter One provided an overview of the rationale and context in which this study took place. In the present chapter, a review of the literature that relates to the research topic, experiences of parents whose children with ASD are starting primary school, is discussed. In section 2.2, an outline of the theoretical underpinning of the present study, Bronfenbrenner's bioecological theory (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006) is presented. Section 2.3 presents the preliminary search of the literature on transitions. In section 2.4, an outline of the manner in which key literature was identified for critical review is provided, while Section 2.5 describes the critical review. In section 2.6, a summary of this chapter is presented.

2.2 Theoretical underpinnings to transitions

The literature on children starting school is framed primarily within a body of research relating to transitions and children's experiences of transitions. The perspectives of the parent in the process are less well described. While the child's personal characteristics and attributes should be important considerations, I would agree with others that there has been a move away from within-child characteristics such as school-readiness to approaches which acknowledge the impact of contextual factors such as school and family features on the transition process (Dockett & Perry, 2001; Rimm-Kaufman & Pianta, 2000; Rous et al., 2005). For the purposes of this study, the most relevant theory for the exploration of parents' experiences of their children starting school was considered to be the bioecological theory developed by Bronfenbrenner (Bronfenbrenner & Morris, 2006); this is discussed in the following sections.

2.2.1 Bioecological approach to transition

The transition to school is a process which begins before, and ends after, the child starts school. A number of individuals are involved in the process,

including the child, their parents, caregivers, and educators. The transition process takes place across a number of ecological contexts, including the family, preschool, and school settings. Bronfenbrenner and Morris's (2006) bioecological theory captures the complexity of the process of the interactions between individual and environment as occurs in the child's transition to school. Building on the original ecological model (Bronfenbrenner, 1979) which sought to conceptualise the role of the individual within the context of their development, Bronfenbrenner and other theorists developed the bioecological model (Bronfenbrenner, 1994; Bronfenbrenner & Morris, 2006). According to Bronfenbrenner (1994, p.38):

Human development takes place through processes of progressively more complex reciprocal interaction between and active, evolving biopsychological human organism and the persons, objects, and symbols in its immediate environment.

Bronfenbrenner and Morris (2006) referred to proximal processes which were interactions between the individual and activities or others in the immediate environment; these included such processes as parent and child interactions and the learning of new skills. Proximal processes were posited as the primary mechanisms driving human development in this conceptualisation. The manner in which proximal processes might shape development was seen to vary as a joint function of the characteristics of the person, of the environment in which the processes were taking place, and the nature of the developmental outcomes under consideration.

In the bioecological model, the individual is seen to be situated within multiple inter-related contexts, viewed as a dynamic nested system of relationships (Bronfenbrenner, 1986). Bronfenbrenner's nested system comprised the microsystem, mesosystem, exosystem, macrosystem, and chronosystem, which are described in more detail below. These are discussed with reference to their relevance to the exploration of parents' experiences of their children with ASD starting school.

2.2.1.1 Microsystem

According to Bronfenbrenner (1994), the microsystem was a pattern of activities, social roles, and interpersonal relations. In the present study, proximal processes refer to interactions between parents and children, parents and professionals, and parents and family members.

2.2.1.2 Mesosystem

The mesosystem referred to a system of links and processes which occur between two or more microsystems, for example, between the school and family, and between the family and the child's service providers in the case of children with disabilities. Child and family characteristics are important, in that the nature of the child's difficulties will determine the type and level of support they require, while the family's resources and ability to cope will impact on their engagement with service providers. The mesosystems of school and voluntary agencies providing services to children with ASD are governed by broader funding and regulatory systems. In the present study, participants talked about their involvement with mesosystems including those of school and health services.

2.2.1.3 Exosystem

The exosystem referred to linkages and processes taking place between two or more settings, one of which contains the developing person and others which don't, for example, the parent's workplace. The exosystem comprises the legislative and regulatory framework as well as the policies and procedures that govern services and the funding structures underpinning service provision. The Irish state, for example, endorses policies that promote inclusion and access to equal opportunities in education and social spheres. At legislative and policy level, the state mandates certain provisions for children with ASD in health and education sectors, including the provision of **support** and resources in schools. In this study, participants described interactions with representatives of government departments such as the SENOs who represent the DES.

2.2.1.4 Macrosystem

The macrosystem is the level that represents the overarching pattern of micro, meso, and exosystems. It includes such features as cultural belief systems, societal norms, bodies of knowledge, and material resources. In Ireland, ASD is currently viewed by the state and its functionaries as a disability and this has impacted on government policies in relation to ASD and the kinds of provision in health and education sectors that is made for children with ASD. ASD, like other disabilities, is constructed within a combination of biomedical and social paradigms. In the current study, participants spoke of their own understanding of ASD, how they felt it conflicted with broader conceptualisations of the condition, how others viewed their children because of their ASD.

Figure 2.1 illustrates how the child is situated in the microsystem of the family in Bronfenbrenner's ecological theoretical framework.

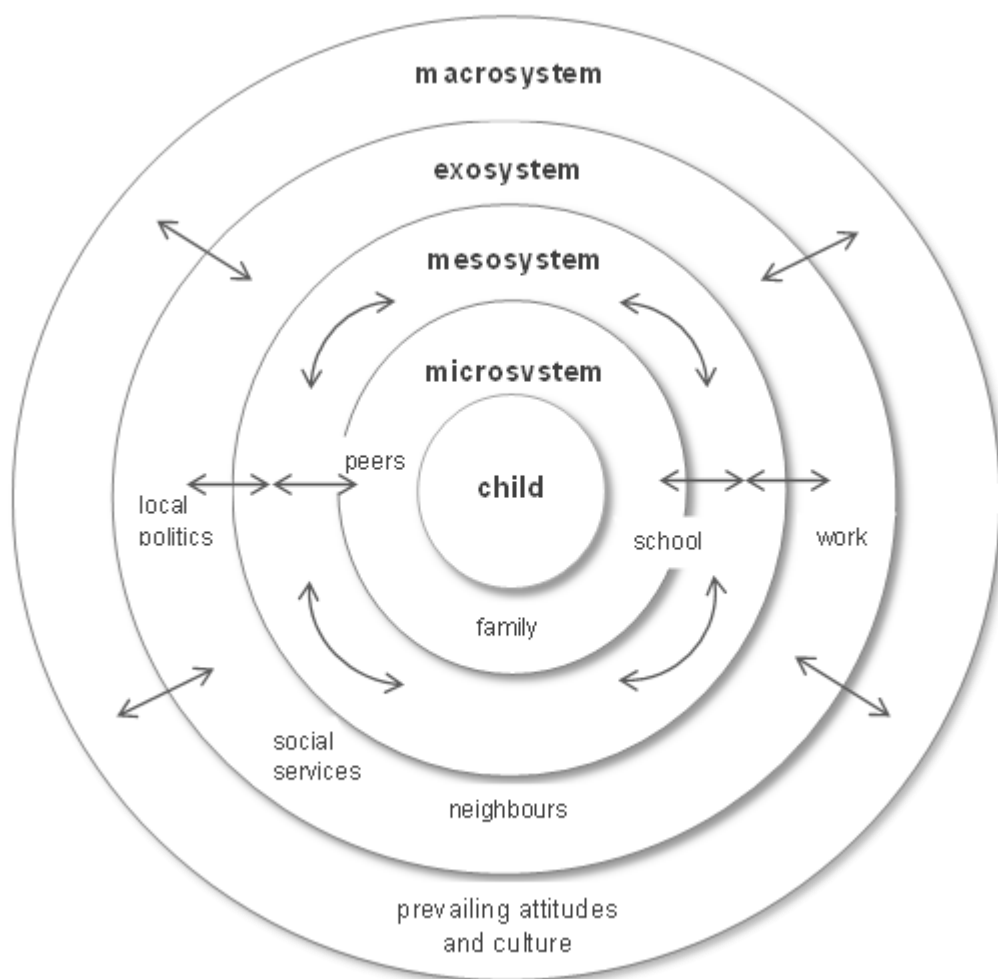


Figure 2.1 Ecological model (after Bronfenbrenner, 1979)

2.2.1.5 Chronosystem

Bronfenbrenner reviewed and refined his own model as time passed (Bronfenbrenner, 1986) and latterly identified an additional system, the chronosystem, which described the interaction between an individual and their environment over time. Time was seen not only a property of the person's development, but was also a property of their ecosystem. In this model, the life transition is the simplest form of **a** chronosystemic event.

Bronfenbrenner (1986) distinguished between normative (usual) and non-normative (unexpected) transitions, both of which occur through the lifespan and “often serve as a direct impetus for developmental change” (Bronfenbrenner, 1986, p. 724). In other words, transitions can be instrumental in advancing development.

In the case of parents of children with ASD, they experience non-normative as well as normative transitions. The child's diagnosis with ASD is a non-normative event, with resulting implications for parents. Studies have found that parents of preschool children with ASD face a number of challenges, including understanding and accepting their child's diagnosis, dealing with the emotions and life changes that a diagnosis brings, searching for appropriate support services and interventions, and choosing optimal educational placements for their child (Cassidy et al., 2008; Keenan, Dillenburg, Doherty, Byrne, & Gallagher, 2010; McConkey & Cassidy, 2010; Murphy & Tierney, 2006).

A feature of transition models such as those of Rous et al. (2005), mentioned previously, is the emphasis on the role of the family rather than on the parental role in the process. The family perform a number of functions on the child's behalf, including providing the context for the child's development, providing the necessary resources and support to facilitate the child's successful transition across contexts, and advocating for the child. The role of parents seems to be subsumed within the family context, and therefore, the individual perspective or agency of the parent is not explicitly acknowledged. Without the conceptualisation of the parent's unique and individual place in models of the transition process, it is difficult to see how an exploration of the

individual parent's attitudes, expectations, experiences, and perspectives can be conducted.

For the purposes of this study, an alternative lens is used as a way of viewing the parent's position in the transition process. The present study used the bioecological model to position parents at the centre of the family microsystem in an equal position to that of the child, that is, as individuals who continue to develop throughout their lives. Figure 2.2 illustrates this perspective.

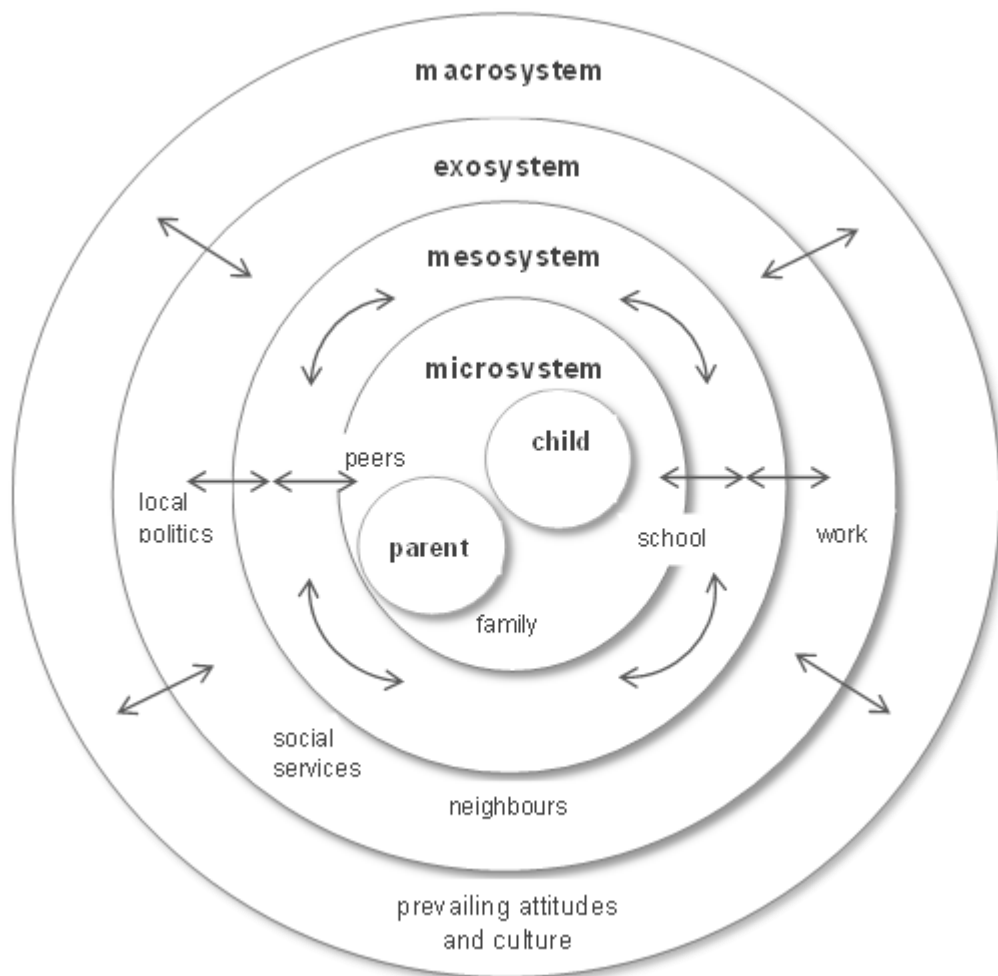


Figure 2.2 Parents and child within the family system (after Bronfenbrenner, 1979)

Subjective experience was an important feature of the bioecological model as is illustrated in the following extract:

In the bioecological model, both objective and subjective elements are posited as driving the course of human development; neither alone is

presumed sufficient ... It is therefore important to understand the nature of each of these two dynamic forces, beginning on the phenomenological or experiential side (Bronfenbrenner & Morris, 2006, p. 797).

Bronfenbrenner and Morris (2006) maintained that both subjective experience and contextual features in a person's life must be considered when examining influences on an individual's development. They distinguished between two aspects of the phenomenological side of the bioecological model, whereby the term experiential referred to cognitive development occurring due to changes in how the environment is perceived at successive stages in the life course, and the term experience referred to feelings and personal beliefs. The findings in the present study comprise both of these aspects of subjective experience. Participants talked about the sense they made of events and experiences in their lives. They also talked about their feelings and reactions to events and other people in their lives. The parent's connections with others and their perceptions and feelings of life changing experiences, such as their children starting school, can be explored within this framework. Having discussed the theoretical framework, the search procedure for the literature review is presented.

2.3 Preliminary overview of literature on transitions to primary school

The following sections provide an overview of what a preliminary search of the literature revealed about transitions to school for children with and without ASD.

2.3.1 Literature on children starting school

Starting school can be a challenging time for any child and so there is a large body of research into what is considered a key period in a child's development (Entwisle & Alexander, 1989). According to Rimm-Kaufman and Pianta (2000) "The entrance into formal schooling is a developmental process that involves tensions between change and stability and between adjusting to new challenges and preserving old patterns" (p. 505). Research into starting school suggested that a positive start is critical to children's long term well-being (Entwisle & Alexander, 1993).

A review of the literature on children starting school found that much of the research focused primarily on the concept of transition (Conn-Powers, Ross-Allen, & Holburn, 1990; Dockett & Perry, 2001; Kagan & Neuman, 1998). Kagan and Neuman (1998) defined transitions as the continuity of experiences that children had between periods and between spheres of their lives. They noted that children needed support when making different transitions such as 'vertical' and 'horizontal' transitions; vertical transitions occur when a child moves from one level or agency to another, as in the transition to school. Horizontal transitions are daily movements between different settings and situations.

For some children the transition to formal schooling is seen as a more complex and critical event. Research on transitions for children from low income families and ethnic minorities (Alexander & Entwisle, 1988; Entwisle & Alexander, 1993) and literature on children with disabilities starting school (M. J. Hanson, 2005; McIntyre, Blacher, & Baker, 2006) suggested that these children were vulnerable in the transition process; they faced challenges starting school which could impact on future success in education. Attempts have been made in the literature to identify factors which impact on children's adjustment to formal schooling with implications for policy and practice. A number of programmes have been devised to enhance children's development and school-readiness including Head Start, the US initiative to boost the school readiness of low-income children (Puma et al., 2010).

Much of the original research into children starting school focused on the notion of school readiness, which was defined as both readiness for school and readiness to learn, two concepts which were thought to be inherent to the child (Carlton & Winsler, 1999). While this concept is still evident in practice (McGettigan & Gray, 2012; O'Kane & Hayes, 2006), there has been a shift in emphasis from studying within-child characteristics to a bioecological formulation such as that proposed by Bronfenbrenner and Morris (2006). The use of the bioecological model as a theoretical framework for transitions to school reflects a growing awareness by researchers of the impact of the child's context, and the changes and relationships within that context, on the child's adjustment to the formal school setting (Cowan, Cowan, Ablow, Kahen Johnson, & Measelle, 2013; M. J. Hanson, 2005; Rimm-Kaufman & Pianta,

2000). The study of teachers' attitudes by O'Kane and Hayes (2006) suggested that within-child attributes and school readiness were still rated by educationalists in Ireland as having high importance in the child's successful transition to primary school.

2.3.2 Literature on children with ASD starting school

Transitions pose particular challenges to children with ASD. Forest, Horner, Lewis-Palmer, and Todd (2004) maintained that children with ASD were "particularly vulnerable" (p.103) in the transition process because of their social and communication difficulties and difficulties generalising skills learned from one setting to another. According to Weiss and Pearson (2012), ensuring smooth transitions was important for this group of children and so professionals in education were advised to look through a family lens and develop collaborative relationships with families to better serve the child and maximise their success in school.

While the vertical transition described above can be a challenging experience, many children with ASD may find horizontal transitions challenging; furthermore, horizontal transitions were reported to be of more concern to parents (Stoner et al., 2007).

2.3.3 Literature on the experience of parents whose children with ASD are starting school

Starting school has been represented as a major event which has symbolic meaning for children and families as it is an important developmental milestone which brings along new demands (Quintero & McIntyre, 2011). The transition period was time-consuming and stressful for families of children with ASD (Weiss & Pearson, 2012). Families of all children were asked to "learn new routines, rules, and faces; negotiate new schedules and services for their child, and cope with the stress that accompanies leaving a familiar, supportive preschool environment" (Conn-Powers et al., 1990, p. 91). According to Parsons, Guldberg, et al. (2009) transitions between and within settings, should be recognised as a source of extreme stress and vulnerability for the child with ASD and for their family. In my experience as an EP, parents have expressed

anxiety about finding the right place for their children and concern about how their children will get on in school.

Conn-Powers et al. (1990) suggested that studies into reducing parent concerns during kindergarten transition would address a large gap in the empirical literature while Kourkoutas, Langher, Caldin, and Fountoulaki (2012) recommended that parents' experiences of accompanying a child with autism through the lifespan should be taken into consideration when designing, improving, and implementing comprehensive educational and health services.

Having discussed the first phase of the literature review, I will discuss the second phase, which involved a critical review of research into parents' experiences around their children with ASD starting school.

2.4 Search procedure for the critical literature review

In this section, the search procedure for the second phase of the literature review is described, including the method and the criteria by which literature was judged to be included or excluded in the critical literature review. When searching the literature in relation to the specific topic of transitions to primary school for children with ASD and the experiences of parents, the focus was narrowed to include recent research and literature over the ten years from 2004 to 2014. Relevant policy documents and unpublished texts such as doctoral theses were included as the literature on the topic was sparse. Books and publications with relevant information were also consulted. Searches were undertaken periodically over a three-year period with the most recent research undertaken in July 2014.

The literature search was conducted electronically using EBSCO, the online research database, as the host database. Selected databases included Academic Search Complete, Education Research Complete, PsycARTICLES, PsychINFO, Education Resource Information Centre (ERIC), and Child Development and Adolescent Studies. The online database Google Scholar was used to ensure thoroughness in identifying key literature. The electronic platform for accessing theses, Ethos, was used to search for relevant unpublished theses.

Key search words and terms such as "children with autism / ASD starting primary school", "children with autism / ASD transitioning to primary school",

“parents experiences of transitions and children with autism / ASD”, and “parents experiences of children with autism / ASD starting school” were used. A template was devised to systematically record the results of the searches and these are provided in the tables 2.1, 2.2, and 2.3 below.

2.4.1 Inclusion criteria for research literature

A template was devised based on the National Institute for Health and Care Excellence (NICE) methodology checklist for qualitative studies (NICE, 2012) as a means of assaying the relevance and rigour of the research literature to decide what should be included in the literature review. The template used for qualitative studies can be seen in Table 2.4. Separate templates were used for quantitative and mixed methods studies and these can be viewed in Appendix 2.

Inclusion criteria were as follows: Studies confined to exploring the experiences of parents of children with disabilities and / or ASD starting primary school; studies with sufficient information on their method, outcomes, and quality; publications that provided contextual, theoretical, and conceptual information to support the exploration of the topic under review; publications in English, and literature that was published in the years 2004 through to 2014.

2.4.2 Exclusion criteria for research study

Research studies were excluded from review on a number of bases as follows: that they were not in English, that they were published prior to 2004, that they did not adequately meet the inclusion criteria as described above, and that they were descriptive or theoretical arguments. Studies that referred to transitions from primary to secondary school or from secondary school to adulthood were excluded as they were considered qualitatively different experiences.

2.4.3 Identification of relevant research studies

Table 2.1 presents the findings from the literature search carried out using the EBSCO database. Potentially relevant studies were identified based on a perusal of abstracts retrieved using the search method described in section 2.4. The search was exhausted at the first 20 studies as studies following this

sample decreased in relevance. A more detailed description of the literature search can be seen in Appendix 1. Studies were then examined for references to further relevant studies.

Table 2.1 Literature search using EBSCO database

Database	EBSCO
Search terms	"Children with autism starting primary school" "Children with ASD starting primary school" "Children with autism transitioning to primary school" "Children with ASD transitioning to primary school" "Parents experiences of transitions and children with ASD" "Parents experiences of transitions and children with autism" "Parents experiences and children with autism starting school" "Parents experiences and children with ASD starting school"
Initial results: First 20 articles surveyed under each search term; Relevant topics N = 6	<ol style="list-style-type: none"> 1. Lilley, R. (2012). It's an absolute nightmare: Maternal experiences of enrolling children diagnosed with autism in primary school in Sydney, Australia 2. Denkyirah, A., Agbeke, W. (2010). Strategies for transitioning pre-schoolers with ASD to kindergarten. 3. Beamish, W., Bryer, F., Klieve, H. (2014). Transitioning children with autism to Australian schools: Social validation of important teacher practices. 4. Keenan, M., Dillenburger, K., Doherty, A. (2010). The experiences of parents during diagnosis and forward planning for children with ASD. 5. Stoner, J., Jones Bock, S., Thompson, J. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals.
Inclusion criteria:	<i>Exploring the experiences of parents of children with disabilities and / or ASD starting primary school; sufficient information on method, outcomes, and quality; contextual, theoretical and conceptual information to support the exploration of the topic under review provided; peer reviewed; 2004 – 2014</i>
Exclusion criteria:	<i>Not in English; Published prior to 2004; that they did not adequately meet the inclusion criteria as described above; referring to transitions from to secondary school or to adulthood; descriptive or theoretical arguments.</i>
Suitable references for review: N = 1	Lilley, R. (2012). It's an absolute nightmare: Maternal experiences of enrolling children diagnosed with autism in primary school in Sydney, Australia

The above literature search yielded five results, as outlined in the table above, which related to the transition of children with ASD to primary school and / or the experiences of parents of young children with ASD. On closer examination, one study met the inclusion criteria and was considered suitable for critical review. Denkyirah and Agbeke (2010) surveyed preschool teacher's

perceptions of the transition process for children with ASD in the US and Ghana but this survey did not include parents' perspectives of the process and was therefore excluded. The study by Beamish, Bryer, and Klieve (2014) on children with ASD in Australia similarly investigated the transition process from the perspectives of educators rather than parents. Keenan et al. (2010) investigated the experience of parents of children with ASD during diagnosis and forward planning. Their study did not relate to transition experiences and so was excluded. Stoner et al. (2005) examined parents' experiences of their interactions with educational professionals; this study was excluded on the basis that it did not refer specifically to the transition process.

Perusing Lilley's (2012) paper yielded another search result; Lilley (2014) discussed mothers' experiences of negotiating primary school placements for their children with autism. This paper was considered relevant and was included in the review. Having reviewed the literature using EBSCO, the online database Google Scholar was used to ensure thoroughness of the search. The same search terms as used in the EBSCO search were used. The results of this search are outlined in table 2.2 below.

Table 2.2 Literature search using Google Scholar

Database	Google Scholar
Search terms	<p>“Children with autism starting primary school”</p> <p>“Children with ASD starting primary school”</p> <p>“Children with autism transitioning to primary school”</p> <p>“Children with ASD transitioning to primary school”</p> <p>“Parents experiences of transitions and children with ASD”</p> <p>“Parents experiences of transitions and children with autism”</p> <p>“Parents experiences and children with autism starting school”</p> <p>“Parents experiences and children with ASD starting school”</p>
Initial results: First 20 articles surveyed under each search term; Relevant topics N = 5	<ol style="list-style-type: none"> 1. Stoner, J., Angell, M., House, J., Jones Bock, S. (2007). Transitions: Perspectives from parents of young children with autism spectrum disorder (ASD). 2. Stoner, J., Jones Bock, S., Thompson, J. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals. 3. Parsons, S., Lewis, A., Ellins, J. (2009). The views and experiences of parents of children with autistic spectrum disorder about educational provision: Comparisons with parents of children with other disabilities from an online survey 4. Forest, E., Horner, R., Lewis-Palmer, T., Todd, A. (2004). Transitions for young children with autism from preschool to kindergarten 5. Quintero, N., McIntyre, L. (2011). Kindergarten transition preparation: A comparison of teacher and parent practices for children with autism and other developmental disabilities
Inclusion criteria:	<i>Exploring the experiences of parents of children with disabilities and / or ASD starting primary school; sufficient information on method, outcomes, and quality; contextual, theoretical and conceptual information to support the exploration of the topic under review provided; peer reviewed; 2004 – 2014</i>
Exclusion criteria:	<i>Not in English; Published prior to 2004; that they did not adequately meet the inclusion criteria as described above; referring to transitions from to secondary school or to adulthood; descriptive or theoretical arguments.</i>
Suitable references for review: N = 4	<p>Stoner, J.; Angell, M.; House, J.; Jones Bock, S. (2007). Transitions: Perspectives from parents of young children with autism spectrum disorder (ASD)</p> <p>Parsons, S.; Lewis, A.; Ellins, J. (2009). The views and experiences of parents of children with autistic spectrum disorder about educational provision: Comparisons with parents of children with other disabilities from an online survey</p> <p>Forest, E.; Horner, R.; Lewis-Palmer, T.; Todd, A. (2004). Transitions for young children with autism from preschool to kindergarten</p> <p>Quintero, N.; McIntyre, L. (2011). Kindergarten transition preparation: A comparison of teacher and parent practices for children with autism and other developmental disabilities</p>

The search using Google Scholar yielded five results relating to the research topic as listed in the table above. On application of inclusion and exclusion criteria, four studies were considered suitable for review; the previous

search had excluded the Stoner, Jones Bock and Thompson (2005) study. As one of the studies included had already been identified in the EBSCO search, a total of six peer-reviewed research articles relevant to the topic under review were identified in total in the search of the databases and papers. To ensure a comprehensive review, a search of relevant doctoral theses was conducted using Ethos, the online thesis search engine. Results of this search are detailed in the table 2.3 below.

Table 2.3 Results from search using Ethos

Database	Ethos
Search terms	“Children with autism / ASD starting primary school” “Children with autism / ASD transitioning to primary school” “Parents experiences of transitions and children with autism / ASD” “Parents experiences and children with autism starting school”
Relevant results: N = 1	1. Miles, K. G. (2012). An exploration of the transition from nursery to primary school for children with autism spectrum conditions (ASCs): Parents’ perspectives.
Inclusion criteria:	<i>As previously</i>
Exclusion criteria:	<i>As previously</i>
Suitable references for review: N = 1	Miles, K. G. (2012). An exploration of the transition from nursery to primary school for children with autism spectrum conditions (ASCs): Parents’ perspectives.

The search of Ethos yielded one result relevant to the topic in this study. Miles’s (2012) doctoral dissertation was reviewed under the inclusion and exclusion criteria and was included for the purposes of illuminating the topic. This study is included with the caveat that it is not peer-reviewed. Given that the literature found relating directly to the research topic was sparse, it was decided to broaden the scope of the literature search to see if studies involving the experiences of parents of children with disabilities would shed additional light on the topic. To this end, the same method was employed as described above to search the electronic databases; search terms such as “parents and children with disabilities starting / transitioning to school / kindergarten” were used. This search yielded two additional studies considered relevant to the topic under review, *Starting school: The importance of parents’ expectations*, which was carried out by Russell (2005) in the UK and *Factors associated with the effective inclusion of primary-aged pupils with Down’s*

syndrome by Fox, Farrell, and Davis, (2004). Having completed a thorough search of the literature, the studies identified were assessed in terms of quality and relevance and included or excluded from the critical literature review using the quality checklists based on the NICE guidelines mentioned previously. Table 2.4 illustrates how Lilley's (2014) paper was assessed using the checklist for qualitative studies.

Table 2.4 Template for checking quality in qualitative studies

Date of research: 2014		Author (s): Rozanna Lilley		
Title: Professional guidance: maternal negotiation of primary school placement for children diagnosed with autism				
Relevance to current study	Topic / Theory / Participant group / Domain (health/education)			
Research publication	Book / Book chapter / Journal article / Other			
Research type	Analysis/ exploration	Survey	Literature review	Intervention
Research aims	Exploration of how different forms of professional guidance impact on maternal negotiation of finding an appropriate school placement for their child with ASD			Clearly stated? Yes
Methodology	Appropriate to study? Yes; but no epistemology; reflexivity	IPA	Grounded theory	Other Narrative analysis
Data collection	Methods clearly described No	Appropriate to research question Yes	Systematic Method not described adequately	Validity? Not able to determine
Literature review	Discussion of previous literature Yes	Link to previous literature Some links to own research and literature but not clearly linked in conclusion		
Outcomes	Claims made about the experiences of mothers of children with ASD starting school in their attempts to find the best place for their child; experiences limited to negotiations and interactions with professionals in Australia; some of the claims resonated with this researcher's experience in practice and in what participants in this study experienced.			
Quality	Rigour Difficult to assess – not enough info about method and theoretical links	Relevance Yes	Suitability for inclusion With caveat re: rigour	Role of researcher Described but not in detail, no ref. to epistemology, reflexivity.
Summary of main findings	In analysing child's transition, agency of mothers need to be acknowledged; relations between professional and powers discussed in terms of power differentials; ASD matrix and democratisation of ASD – professionals now equally offer information but this can be conflicting and confusing.			

Please refer to Appendix 3 to view quality checklists for the other studies critiqued. Using the quality checklists, eight peer-reviewed research papers and one doctoral thesis were included for review. These are critiqued in the following section.

2.5 Critical review of the research literature

In this section, the research papers identified in the literature search are discussed. The papers are organised within the following framework, studies that looked at the experiences of parents of children with disabilities (ASD and Down's Syndrome (DS)) around educational provision for their children, studies that explored parents' experience of transition practices, and studies that explored parents' experiences and perspectives of their child starting school.

2.5.1 Parents' experiences of educational provision

A search of the literature on parents' experiences of transitions yielded two studies that focused on parents' experiences of educational provision. In the first study reviewed, Parsons, Lewis, and Ellins (2009) conducted an on-line survey to compare the views of parents of children with ASD and those of parents whose children did not have ASD around educational provision. This study formed part of a broader project investigating the views and experiences of families of children with disabilities in Great Britain.

A review of the literature for the purposes of the study revealed "mixed messages" (Parsons, Lewis, et al., 2009, p. 39) about whether parents of children with different disabilities had different experiences of special education or whether they faced similar frustrations and challenges.

Five themes, reflecting different strands of the overall project, were selected around which the survey questions were devised. These included (a) independence and autonomy, (b) experience and accessibility, (c) attitudes and behaviours, (d) knowledge and assertion of rights, and (e) ambition and aspirations. There were 125 respondents in all, whose children ranged in ages from five to 16 years of age. Sixty six respondents had children with ASD and 59 were parents of children who did not have ASD.

Results indicated that the majority of participants were satisfied with their child's current educational provision; the children attended the school of their parents' choice and most participants had neutral or positive attitudes in relation to how the schools had accommodated their children. Two interesting results emerged in relation to the views of parents of children with ASD; they were more likely to report that their children had additional support needs and they were more likely to have concerns that school staff should have knowledge of their child's condition. Parents of both groups agreed that their children would have difficulties getting a job but disagreed that they would have difficulties continuing in education in the future. In relation to transitions between schools, both groups indicated concerns around their children making transitions.

Parsons, Lewis, et al. (2009) discussed the limitations in their methodology which included the composition of respondents being skewed towards professional, middle class people. People who were not computer literate, did not have access to the internet, or did not have contact with relevant support groups or websites could not have taken part. Respondents were self-selected and may have represented people with strong views about the topic. This may influence the findings and limits the representativeness of the sample. In reviewing the study, a number of additional limitations were noted; a detailed statistical analysis was conducted on the data to compare the views of parents of children with and without ASD, however this had not been the initial objective. Following a preliminary data analysis, which showed a relatively even split between respondents who were parents of children with ASD and those who were not, the decision was made to conduct a comparison between their experiences and views. The impact of conducting a post-hoc comparative analysis was not explored; this may have influenced the objectivity of the findings. Respondents had children who attended both mainstream and special school placements. The objective of the study was to explore parental views of educational provision but the views of parents of children attending these very different settings were not compared and no reference was made to differences that may arise between the groups. Furthermore, no reference was made to theoretical or epistemological considerations.

This study did not directly examine the experiences of parents whose children with ASD were starting school but it did investigate parental views and

perceptions of educational provision. Of note is that some parents of children with ASD and parents of children with disabilities have concerns about transitions in educational provision and that these continue through school. In the section below, studies that explored parents' experiences of transition practices are discussed.

In the second study, Fox, Farrell, and Davis (2004) investigated the factors that affected the inclusion of children with DS in primary school. This study used mixed methods to look at the cases of eighteen children with DS. A variety of perspectives in the process of inclusion were sought, including conducting focus groups with stakeholders, interviews with parents, observing children with DS in school and interviewing children with DS about their experiences. To find out about the attitudes of classmates, a sociometric assessment was conducted. The interviews revealed that most parents referred to a struggle in finding mainstream provision for their children. Parents interviewed felt that teaching assistants (TAs), the UK equivalent of SNAs, were crucial to the child's effective inclusion. Some parents in the study expressed concern at the poor liaison between school staff and themselves. A small minority reported feeling unable to discuss concerns with staff. The study identified the following features of the school that promoted successful inclusion: the centrality of the teacher in the process of including the child, complementary relationships between support staff and the class teacher, the capacity of the class curriculum to include the child, and the quality of communication between teacher and pupil, teacher and TA, teacher and advisory teacher, and teacher and parents/carers.

A detailed data analysis of each case was conducted before a comparative analysis across cases was undertaken. The study has merit in its scope and the comprehensive data collection including eliciting the perspectives of children with DS and their peers. It is interesting to note similarities with issues described in the literature for parents of children with ASD, namely the struggle to find mainstream places, and issues liaising and communicating with school staff. In the next section, parents' experiences of transition practices are discussed.

2.5.2 Parents' experiences of transition practices

In this section, three studies that explored parents' experiences of transition practices are outlined. Transition practices refer to activities that are linked to successful outcomes that address child, family, staff, programme, and community activities (Rous et al., 2005).

In the first study, Forest et al. (2004) looked at transitions for young children with autism from preschool to kindergarten. The primary aim was to examine an instrument, the Elements for Transition to Kindergarten (ETK), devised to measure transition practices. A summary of 25 transition elements identified from the literature as being important for successful transitions was compiled to inform the development of a survey instrument. The transition elements included such practices as creation of an initial transition timeline and selection of specific kindergarten placement. The instrument was used in interviews with parents, preschool teachers and kindergarten teachers of three young children with ASD in order to identify important elements in the transition process. An index of importance was devised to see if elements identified in the literature were perceived as important by the people involved in the process. A high level of agreement around importance was reached between teachers and parents across all elements except one, in which school placement was defined at least six months before transition. Interestingly, teachers rated a meeting between preschool and kindergarten teachers prior to transition as being more important than parents did.

While the study's objective was to evaluate a survey instrument, the experiences of three parents of young children around the transition process were part of the exploration. Parents and teachers rated the 25 target elements as having high importance. However, parents felt many elements in the transition process had not **been** implemented. Though the overall experience of the transition process had been largely positive, there was a question about whether this was due to the ability of the focus children; children with greater needs may not have experienced such a positive transition.

Limitations in the study were discussed. The study was conducted on a small-scale, was non-randomised and participants were purposively sampled; therefore, results could not be generalised. The study did not assess the test-retest reliability of the survey instrument and links were not made between

transition practice and transition success. In addition, whilst a high correlation was found between what the literature says about successful practices and what parents and educators thought was important; many of the transition elements had not been implemented in the children's transition processes. Furthermore, as the focus children were high functioning, questions remained about the relevance of the instrument to children with ASD who would not be as able and, in whose cases, certain transition practices would not be implemented.

Forest et al. (2004) reported that their findings validated findings in the literature about the importance of certain transition practices. Key recommendations included an emphasis on the transition process spanning more than a year beforehand, the identification of the roles of transition team members, and that transition practices should be targeted for accomplishment. Families, teachers and administrators were encouraged to use the instrument to monitor progress in the transition process. In this study, the experiences of parents were not explored in detail. Nevertheless, the findings shed some light on the importance of adopting certain key transition practices to support parents and children with ASD in starting school.

The second paper under discussion in this section also involved a survey-based study. Quintero and McIntyre (2011) compared teacher and parent practices for children with autism and other developmental disabilities (DD). A primary goal of the study was to investigate teacher concerns regarding the young children's transition to kindergarten. In the search of the literature, only two published studies were found that examined the transition to primary school for children with autism; one of which was Forest et al.'s (2004) survey, discussed above.

In this study, preschool teachers ($n = 43$) and parents of 95 children with disabilities, 19 of whom had ASD, were purposively selected for the survey. Data were collected at two points in the year prior to the children's transitions to primary school. At the first point of data collection, parent and teacher reports were elicited. Parents completed three questionnaires to collect their experiences. One of the questionnaires surveyed parent transition practices using the Family Experiences and Involvement in Transition questionnaire (FEIT), an instrument devised by one of authors previously. Two other

questionnaires, which were neither named nor described, measured parenting stress, and information on the transitioning child's behaviour.

The preschool teachers were asked to complete a brief demographic form and a transition measure devised for the study, the Teachers Perceptions on Transition (TPOT), for the children they taught. This instrument asked questions such as how long the teacher had known the student and questions relating to the use of 15 common transition practices. These practices included transition planning meetings and home visits prior to transition. Open ended questions were included to ask teachers about concerns they had relating to the children's transitions. Open ended questions were analysed and coded by two research assistants. Data analysis of descriptive and inferential statistics collected during the study was conducted using the software statistical package, Statistical Package for the Social Sciences (SPSS).

The second data collection point involved 45 parents from the original cohort taking part in a follow up assessment of their experiences and involvement in the children's transition from preschool to kindergarten. The same questionnaires were completed as in the first data collection point.

Results of the study indicated that teachers were significantly more likely to report higher concerns for the transition of children with ASD than for children with DD. There were no differences in teacher transition practices between the groups save for one; teachers felt children with ASD should visit their kindergarten classroom before starting school.

No significant differences were found in parental involvement in transition practices between the two groups at either time point although the study found that parents of children with DD were more likely to report participating in a transition planning meeting than their counterparts in the ASD group at the first time point. At the second time point, parents of children with DD reported that they received written communication regarding the transition from the kindergarten programme significantly more than parents with ASD. This seems to suggest that parents of children with DD received more input around the process of transition than their counterparts with ASD.

Preschool teachers reported that the most common transition practice they wanted but could not have was to have a meeting with the children's new kindergarten teacher. This finding echoes the findings in the study by Forest et

al. (2004). The main barrier to engaging in transition practices such as increased classroom visits and collaboration with counterparts in kindergarten was lack of time. Parents reported that preschool teachers engaged more in transition practices than elementary school staff. Overall findings indicated that preschool teachers and parents engaged in a set of standard transition practices such as frequent communication between home and school and completion of a transition folder with information on the child but these were rarely individualised.

Quintero and McIntyre (2011) outlined a number of strengths in their study. These included collecting cross-informant data from teachers and parents on transition practices. They outlined a number of limitations in their study; the study did not have an experimental design and did not measure the degree to which preschool teachers had received transition training. The sample was quite homogeneous, for example, family and teacher demographics were not varied and therefore the study may not be representative of a broader demographic sample.

Other limitations included the nature of the survey instruments which were not standardised. The children with ASD had a parent-reported diagnosis of ASD which was not corroborated. A review of diagnostic reports might have provided a more rigorous approach to sampling. The sample size in this study was small. At the second point of data collection there were 45 parent participants. No explanation was offered as to why children with DD were more likely to receive more input in terms of transition practices than children with ASD; exploring this issue would have provided a useful insight into the topic considering there was more concern expressed by teachers about the transitions of children with ASD.

Quintero and McIntyre (2011) reported that parents completed measures of stress and child behaviour but these are not reported in this paper. The study was described as preliminary and recommendations were made about future avenues of research such as gaining information about how kindergarten teachers perceive transitions for children with special needs and families' understanding of transition practices. The focus of this study was more on teacher concerns and transition practices than on parents' concerns and perspectives on transitions for their children. While data was gathered on

parental involvement in transition practices, little was discovered about their overall experience of the process. Nevertheless, the study adds some insight into parents' involvement in their children's transitions and their experiences of transition practices.

In the third study in this section, Stoner et al. (2007) investigated parents' perspectives and concerns about transitions for their young children with autism in the US. It was maintained that parent perspectives were a vital tool in successful transition planning. Four married couples (parents of four children aged six to eight years) were selected purposively from a support group for parents of children with ASD. Two of the children were in preschool and two of the children were in elementary school at the time of the interviews.

Stoner et al. (2007) described their method as a qualitative cross-case analysis in which they conducted multiple individual interviews with participants. Each participant was interviewed three times over a nine month period. In the first interview parents were asked about their experiences with educational professionals and in subsequent interviews, themes identified were further probed and explored until theoretical saturation had been reached. Stoner et al. (2007) described in some detail the way in which data was analysed and the method of analysis appears rigorous. Data was analysed using line by line coding by two primary researchers who continuously corroborated and cross-checked their results until they reached agreement. Their analysis was then presented to two other researchers who were experts in the field. They corroborated their data with evidence provided by parents in the form of home-school communication notebooks, samples of strategies used by parents, and by cross-checking between parents and across cases. They did not explicitly state, however, what their epistemology or method was but made reference to Strauss and Corbin (1998) in their description of how the data was analysed; therefore it is concluded that they used a form of grounded theory.

While Stoner et al. (2007) set out to look at parents' perceptions, they reported that they sought a family perspective in the study and so used data from interviews with both partners in each couple to corroborate what each said. Findings from the study indicated that concern about their children's transition was a key recurring theme amongst participants, echoing findings in the Forest et al. (2004) study. Six major themes were identified in the data: (a) child

centred transitions were considered most effective by parents, (b) communication between home and school was a vital link, (c) preparation for transitions began with an understanding of the child, (d) barriers to transitions were identified by participants, which included lack of communication between teacher and child, and lack of preparation and recognition by teachers of the importance of using transition strategies, (e) parents were more focused on horizontal transitions than vertical transitions, and (f) effective transition strategies were identified by parents. Following identification of the main themes, a concept map was devised, in which communication between family and educational professionals was identified as a vital link in the transition process.

Stoner et al. (2007) maintained that input from families was a key factor in the transition process. Understanding family perspectives and including the family in planning for transitions was an integral part of the process. While vertical transitions, such as those from preschool to primary school and kindergarten, were the focus of much of the literature on children's transitions, parents in this study identified horizontal transitions, the daily transitions between tasks and activities, as concerns. Stoner et al. (2007) explained that vertical transitions were often planned and predictable while horizontal transitions could be unpredictable and therefore stressful for children with ASD. Participants reported that by helping the children cope with horizontal transitions, they would facilitate easier vertical transitions. Participants used a variety of strategies, often visually-based, to help children understand what was happening next in a situation, thereby making horizontal transitions easier for the children. Analysis of the strategies parents used to support the children in making transitions identified a three-step process that involved (a) identification of potentially difficult transitions, (b) allowing the child time to explore the transition setting at a time of low stress, and (c) allowing them to explore the setting before the transition occurred. Communication with educational professionals was important for participants as it enabled them to share these important strategies with them.

Stoner et al. (2007) described some limitations in the study. The sample comprised participants who may have been more motivated than a broader pool of participants and therefore it was not possible to generalise to a broader

population. By interviewing married couples only, they did not get the perspectives of unmarried couples, single parents or separated couples.

A number of limitations could be added to those described above. Stoner et al. (2007) were not explicit about the theoretical basis or method used in the study. They interviewed married couples to get the perspective of the family as a unit and to enable corroboration of what both partners said. The rationale for treating couples as a unit, in which members need to corroborate each other is not explained. As this was a qualitative exploration of participants' experiences, it is not clear why one participant should corroborate the individual experiences of another. While the authors stated that they probed differences and disagreement between couples, they did not explain what these differences were, what the purpose of exploring them was, or what the differences could mean. The study did not focus exclusively on vertical transitions such as starting school; Participants were informants on transitions more generally.

This study explored parents' experiences of transition practices and strategies and provided information about parental concerns in relation to transitions; an interesting finding involved parents' concerns about horizontal transitions. In the next section, four studies which relate to parents' experiences of the transition process are presented.

2.5.3 Parents' experiences of the transition process

In this section, studies that explored parents' experiences of their young children starting school are discussed. The review is divided into two parts; in the first part, a study examining the experiences of parents of children with special needs / disabilities around the transition process is presented, and in the second part, three studies exploring the experiences of parents whose children with ASD were starting primary school are discussed. The four studies used primarily qualitative methodologies, including interview methods and case study analysis; in one study, Miles (2012) used a survey questionnaire to further explore findings.

2.5.3.1 Experiences of parents of children with special needs / disabilities around transition to school

Russell (2005) investigated the experiences of parents of children with special needs / disabilities around their children starting school. Bronfenbrenner's ecological model (Bronfenbrenner, 1977) was used as the theoretical underpinning for the exploration of the content, origins and development of parental expectations when their child with a disability started school; the extent to which parents felt their expectations were realised after the child's first year in school was also examined. Framed within an emancipatory research paradigm, nineteen parents of children with a disability were interviewed three times over a 21 month period. Their children comprised 11 boys and eight girls, ranging in age from 21 to 56 months. A range of disabilities was represented and the children were moving to a variety of school settings, ranging from special schools to mainstream schools. Parents were viewed as active participants in the research process. A group of six parents of older children with disabilities formed a parent advisory group (PAG) to offer the researcher support and advice, complete some analysis and discuss findings.

Interviews were semi-structured, with the first taking place at the beginning of the child's statutory assessment. Statutory assessment is a detailed investigation to find out exactly what a child's SEN are and what specialist support is needed in education. The second interview took place just before the child started school. In this interview, participants were asked to describe their experience of the child's statutory assessment and to review a list of their expectations. The third interview was conducted when the child had completed three terms in school; participants were asked to discuss the outcomes of their expectations at this point.

Russell (2005) described how interviews were taped and transcribed but the method of transcription or the manner in which transcribed data was analysed was not detailed. The data was organised in two ways; a profile of each family was built up over the course of the study and was compiled into tabular form to allow a comparison of the data and identification of emerging themes. The content of the interviews was confirmed with participants and they compared their lists of expectations with others in the sample. Fourteen expectations that more than six parents had identified were referred to as the

shared expectations. These expectations included “that their child would learn from other children” and that they would “be included in making decisions” (Russell, 2005, p. 121). In second and third interviews, parents were asked to categorise these expectations according to their importance.

Findings suggested that participants had individual and shared expectations of their children, of support professionals, of local special education systems and procedures around statutory assessment. These were based on personal beliefs about disability and education as well as experiences of their children, services and schools.

Russell (2005) used Bronfenbrenner’s (1977) framework to describe four levels of interaction in the key findings. These levels are the micro, meso, exo, and macrosystems. At the level of the microsystem, participants had expectations of their child’s learning, their inclusion in school, and of information sharing with professionals. Expectations at this level had either been realised or had developed in the first year of school. Most participants had a clearer understanding of their children’s impairments and needs by the third interview.

At the mesosystemic level, findings suggested that participants had expectations around support professionals but only become aware of them when they were not being realised. Mixed experiences of professionals in preschool were identified, with some participants feeling supported by preschool staff and others battling to achieve what they wanted. In terms of shared expectations across the group, communication between school and home, parents’ involvement in decision making and qualities of staff were important. The largest proportion of expectations that had not been realised at the end of the first year concerned relationships with school; some participants enjoyed better communication with school than others. Another important shared expectation involved the commitment and expertise of staff, which were important factors influencing the outcome of participants’ expectations.

Expectations at the exosystemic level were found to be frequently based on incomplete knowledge as most parents had little knowledge of the procedures for children with SEN. For most participants, expectations of the formal school and educational structures and supports were realised by the third interview. The children’s statements of their SEN had contributed to participants’ understanding of their needs as did the children’s progress in

school. Where expectations were not realised at the mesosystemic level, was likely to be associated with the child's support provision. This was considered to be due to participants' lack of knowledge and understanding or lack of opportunity to discuss the organisation of the provision with school staff.

At the macrosystemic level, few participants were reported to have developed expectations around broader socio-political issues. This was considered due to the long-term nature of these concerns.

In addition to the findings described above, the PAG commented on participants' lack of understanding around some of the information given in relation to the children's statutory assessment, the participants' limited experience of disability, and their lack of knowledge and experience in special education.

Russell (2005) found that visiting schools to assess their suitability for their children was emotionally very difficult for some participants. A number of recommendations were made to help parents develop expectations that were likely to have positive outcomes, including provision of accurate written and verbal information; support for parents of children with SEN to visit a variety of schools and spend time in the classroom; professional staff to listen to parents and provide them with additional information around the children's needs; provision of opportunities for parents to discuss their expectations; provision of equality training for professionals and parents and development of an early years transition plan which would focus on the needs of parents and raise awareness of parents' expectations and issues important to families.

Russell (2005) did not discuss limitations in this paper. The study was clearly positioned within an epistemological paradigm and the theoretical base was discussed but there was limited discussion around the method employed and little reference to reflexivity was evident. Russell's (2005) use of member confirmation and the PAG complemented the research framework employed. However, as the primary investigator in a qualitative study and the parent of a child with a disability, it would have been useful if a reflexive approach to data collection, analysis and interpretation had been demonstrated. Nevertheless, a number of interesting points were made in this study in relation to parents' expectations around their children starting school and how these expectations were realised in the first year.

In the following section, studies focusing on the experiences of parents whose children with ASD were starting school are presented.

2.5.3.2 Experience of parents whose children with ASD were starting school

This section includes three studies which focused on exploring the experience of parents whose children with ASD were starting school. The first two studies under discussion formed part of Lilley's doctoral study, *Maternal transitions: When children with autism start primary school* (Lilley, 2012, 2014). Lilley's research design for the overall study was longitudinal and involved up to three individual interviews with 22 mothers over a three year period. Purposive sampling was used to include mothers whose children with ASD had started school at the beginning of the study. Interviews were semi-structured and topics included experiences of the children's ASD diagnosis, early intervention, and processes of securing school placements. Lilley recorded and transcribed the interviews. Interview extracts relevant to the topics of her enquiry were thematically interpreted within a methodological framework broadly based on narrative analysis.

Lilley (2012) explored mothers' experiences of finding a school placement for their children with autism in Sydney, Australia. The narrative analysis was conducted by extracting and analysing texts relating to participants' experiences of stigma and informal exclusion. In this study, particular attention was given to the way autism was perceived by others and the manner in which stigma was experienced by mothers and their children. According to Lilley (2012), mothers of children who were starting school frequently experienced stereotyping, discrimination, and efforts to informally exclude their children from school placements. Autism was reported to be a "deeply discrediting attribute" (Lilley, 2012, p. 515) in the eyes of some educators, leading to discrimination against children with autism.

Lilley (2012) discussed a number of distinct types of stigma in the literature; 'enacted' stigma referred to episodes of discrimination and 'felt' stigma referred to the anticipation of enacted stigma and feelings of shame. 'Courtesy' stigma referred to a type of stigma experienced by those related to stigmatised individuals because of the connection between them. Ten of the participants in the study described the experience of explicit stigma in their

encounters with professionals, such as devaluing comments which were perceived to be discriminatory or deeply threatening to the welfare of the child and sometimes to the mother herself.

Lilley (2012) described a “highly fractured educational field” (p. 518) with tensions between inclusive policies and ongoing commitment to segregated education. A lack of resources to make inclusion work and a competitive educational environment where schools vied for status and funding based on performance complicated the picture. The difficult position for school personnel who were caught between exclusionary practises and inclusive policies was acknowledged; however, it was reported that school professionals used conscious strategies to informally exclude children with autism. Lilley (2012) described two examples of these strategies, one of which was to appeal to the mother’s concern for the good of the child, for example, stating that the school has inadequate resources to meet the child’s needs; the other strategy was to send the child to a school in another school sector, thereby removing the “problem” (p. 522) of the mother and child administratively from the sector.

Mothers in the study talked of the experience as being a “nightmare” (p. 523). Light was shed in the study on the manner in which ASD, as a disability, could be seen as a ‘master status’ (p. 519); the individual’s identity was subsumed in the disability with the result that when a mother disclosed her child’s autism to school professionals, the nature of the conversation around enrolment changed, resulting in exclusion.

Lilley (2012) made reference to her role as researcher in the study. The participants in the study were made aware that Lilley herself had a child with autism. The assertion was made that the mothers’ stories would “undoubtedly have been told very differently” if the researcher had been identified as a “service or education gatekeeper” (p. 517). As the mother of a child diagnosed with autism, Lilley (2012) believed participants saw her as being on their side. Apart from this assertion, a reflexive account of the impact of her role as mother of a child with autism or researcher in interviewing or interpreting participants’ narratives was not presented. Adequate exploration of the researcher’s role in meaning-construction and interpretation of the context in which the narratives occurred was not detailed; this raises questions about whether the researcher’s own experiences clouded her interpretation of participants’ narratives.

Lilley (2012) was uncritical of the narrative accounts that participants offered and the truth claims made. Conclusions were drawn from participants' accounts about what the professionals they talked about were thinking and intending. In this paper, the consequences of an encounter between a participant and an educator who persuaded her against enrolling her child in a certain school were described as follows: "The stereotyping alongside the cautionary tales did their intended work of informal exclusion" (Lilley, 2012, p. 521). The language used to report findings evidenced a degree of bias, for example, schools adopted a "range of exclusionary strategies in the arsenal of stigmatising practices" (Lilley, 2012, p. 523). Participants in this study were described as being "actively pushed around by school gatekeepers who are often intent on keeping out students identified with autism" (Lilley, 2012, p. 524). Lilley (2012) attributed agency to the "powerful education system" (p.524) which used stigmatisation and informal exclusion to "buttress ongoing projects of social exclusion" (p. 524). This practice was seen as part of wider systemic discriminatory practices, ideologies, and intolerance towards students who were perceived to be different. Light was not shed on the proponents or agents of these practices and ideologies; other explanations for the practice of informal exclusion experienced by mothers and their children with autism were not examined other than to cite pressures on the educational system and lack of resources to meet the needs of all students. This study, however, does shed light on the experiences of parents around the difficulties they face finding a school placement and issues with stigma around ASD which are relevant to the topic under review.

In the second of the papers in her study, Lilley (2014) described an exploration of the different forms of professional guidance sought and experienced by mothers who were searching for a primary school placement for their children with ASD. She linked her findings to a theory of an 'autism matrix' (Eyal, Hart, Onculer, Oren, & Rossi, 2010). This matrix described the "democratisation of expertise" (Eyal et al., 2010, p. 2) on autism whereby parents and professionals shared in the production and consumption of knowledge around autism. Lilley (2014) disputed this conceptualisation; findings indicated that mothers in Sydney, Australia, who tried to find a suitable school placement for their children with ASD frequently received conflicting advice from

multiple professionals at a time of considerable stress. The complexity of autism, which lead to different ways of “knowing” (Lilley, 2014, p.12) the condition, and the diversity of disciplinary frameworks, possibly promoted differences of opinion amongst professionals as to what constituted the most appropriate school placement. In addition to conflict around suitability of educational placements, growing pressures on the education system resulted in education professionals adopting “pragmatic strategies” (Lilley, 2014, p. 11) to deny children with ASD access to their schools.

Lilley (2014) described the process of finding an appropriate placement from the points of view of mothers whose children had been diagnosed with cognitive functioning in three distinct categories; students with autism and ID; students with autism and borderline ability, and students with ‘high functioning’ autism. Cognitive functioning was frequently used as a key indicator for school placement and this impacted on the placement choices made by mothers in the study, for example children with high functioning autism were more likely to be directed towards mainstream settings while children with autism and ID were more likely to be directed towards segregated settings such as special schools. Mothers of children with borderline ability experienced the most “intense conflict” (Lilley, 2014, p. 12). Having made their decisions about school placement, some mothers still felt conflicted about the best choice for their children.

Lilley’s (2014) paper shed light on an underexplored topic in the research on transitions. A thorough account of how mothers in this study experienced the process of trying to find a school placement for their children was attempted. The importance of acknowledging and respecting maternal agency at the time of transition was emphasised. The participants in this study were reported to have experienced stress, conflict, and power differentials with professionals in trying to find places for their children. As in the Lilley (2012) paper, the role of the researcher was not explored and no discussion was evidenced around reflexivity, subjectivity, or the ontological and epistemological underpinnings of the research. Though Lilley (2014) used the methodological framework of narrative analysis, the findings were not fully evidenced with many extracts from the interviews conducted.

A thorough reading of Lilley's (2014) paper reveals what seems like a partisan approach to the topic. The use of language was sometimes charged, for example, phrases such as "professionals seek to strike alliances" (Lilley, 2014, p. 2) with parents; mothers "wrestle" (Lilley, 2014, p. 5) with the choices available. In Lilley's (2014) opinion, professional guidance was conflicting; psychometric testing was an "expert tool of the state" and a "crucial weapon in the arsenal of 'appropriate' school placement" (Lilley, 2014, p. 6). Mothers operated within a complex arena from a vantage point of "embattled vulnerability" (Lilley, 2014, p. 13) where professionals knowingly "vie" (Lilley, 2014, p. 12) to influence their decision making or, in some cases, blocked their attempts to choose what they considered suitable placements for their children.

While the two studies described above, add to what is known about mothers' experiences of their children's transition to school in this context, Lilley (2012, 2014) did not explore the experiences of fathers. Furthermore, there may be questions that because she has not been reflexive about the possible impact of her own experiences on interpretation of participants' narratives, her account might be biased by her own perceptions.

The third study in this section was Miles's (2012) exploration of parents' perspectives on the transition from nursery to primary school for children with autism spectrum conditions (ASCs). This study was carried out as part of a doctoral dissertation. Parents of children with ASC who had already started school participated in this mixed method sequential study. Miles (2012) was interested in considering the parental voice in line with current government priorities for supporting children and families with SEN. The study was situated within the context of a local authority (LA) in the UK and sought to inform the practice of professionals within the LA and within the broader national agenda of making improvements for children with SEN. In this way, the study was outcome-focussed and aimed to answer questions, such as giving insight into the support parents require, which could have an impact on future policy and practice within the local area.

Miles's (2012) study was exploratory and inductive and consisted of two phases. In the first phase, IPA was used to carry out a qualitative investigation of parents' experiences and perspectives of their children's transitions to primary school. It was noted in the literature review that there was little to be

found in the UK literature on children transitioning to primary school with, or without, ASC.

Five participants, one of whom had two children with ASC, took part in the study. Questions were asked about parents' planning for their children's education and what they found helpful or unhelpful in the children's transitions to school. Three overarching themes were identified and these were (a) 'Being a parent of a child with ASC', (b) 'Relationships with professionals', and (c) 'Importance of early identification'. Parents discussed the feelings they had in relation to past experiences and feelings about the future, which included upset, worry, hope, acceptance, and coming to terms with their children's needs. Worry about the future was a salient experience for participants. Relationships with professionals were identified as important; valued features of these relationships included trust, communication, which allowed participants to seek the professional's opinions and expertise. 'Importance of early identification' was a theme that reflected participants' experiences around the diagnostic process and obtaining a statement of SEN. Planning for the transition and engaging in transition practices were important parts of the process for parents. Challenges experienced by parents included not having their concerns taken seriously by professionals, and coming to terms with the child's diagnosis and needs.

In the second phase of his study, a quantitative method was used which included devising a semantic differential scale in a questionnaire to further explore the overarching theme 'Relationships with professionals'. This type of scale was used as it measured how individuals attributed meaning to particular concepts rather than measuring levels of agreement among participants. The scale required that the respondent indicated the direction of their feelings towards a number of bipolar adjectives such as happy / sad on a seven-point scale. The questionnaire was administered to 20 families. Findings suggested that, overall, the majority of parents experienced the transition as a positive event.

Miles (2012) discussed limitations in his study, for example, his position as a trainee EP may have inhibited participants in describing their true feelings; furthermore, it was posited that social desirability may have been a factor in the interviews, whereby participants wanted to please the interviewer. To

counteract this, efforts were made to put participants at ease and to minimise the impact of the researcher's own assumptions on the research using strategies such as keeping a reflexive log and availing of regular supervision. Member checking was used with participants to corroborate findings. Reference was to the interpretative and hermeneutic aspects of IPA but these are not well evidenced in the study; it appears that a more pragmatic approach to using IPA was adopted; participants' meaning making was explored in what appears to be a predominantly descriptive and thematic manner. An additional limitation was that, although the use of the questionnaire aided in corroboration and triangulation of the qualitative findings, the scale used was not standardised.

Qualitative methods can add to knowledge in an idiographic, case-by-case manner and therefore Miles's (2012) study has merit in that it sheds light on an under-researched area and increases understanding of the experiences of a group of parents whose children with ASC had started school in the previous year. Though Miles's questionnaire aimed to capture parental experiences of the transition, it was not standardised and was conducted on a small sample size and this would therefore impact on the generalizability of the results. When evaluating this study it must be borne in mind that it has not been peer-reviewed.

Having reviewed the literature, a number of conclusions can be drawn. Parents whose children with ASD are starting school were found to have a variety of experiences, both negative and positive. They faced a number of challenges, including those involving transition practices and process, and those which related to their own personal feelings. The variety of experiences may reflect different emphasis in the research studies, or the context in which the study took place. Some research focused on transition practices while other research focused on parental experiences. Lilley's (2012, 2104) account of mothers' experiences of finding school placements for their children in Sydney, Australia, stood in contrast to other studies because of predominantly negative perceptions of the education system and professionals and the of participants' experience of a variety of stigmatising practices. Other studies reviewed in this chapter showed that a majority of participants were eventually satisfied with their children's educational placement. While the studies critiqued above provide some insight into the experiences of parents around the transition of

their children with ASD to school, none have provided an in-depth exploration of parental experiences, goals, and feelings about their children starting school. This gap is addressed in the current study.

2.6 Summary of Chapter Two

Chapter Two provided an outline of the theoretical underpinning of the study and the literature review. Bronfenbrenner's bioecological model (Bronfenbrenner & Morris, 2006) was viewed as an appropriate theoretical basis for the present research. The child's transition to school takes place across a number of settings over an extended period of time. Various people are involved, including the child, their parents, their family, and professionals. The contexts in which the transition takes place can be related to the bioecological model's contextual features, the micro-, meso- and macrosystems. The model's chronosystem situates the event across a given time period. In this study, the bioecological model was viewed through a different lens, locating the parent at the centre of the microsystem with their child. The bioecological model fits with the epistemology of the study, allowing for the exploration of the individual's phenomenological experiences of the transition and the context in which it occurs.

The search procedure for identifying key literature relevant to the topic under review was described in detail, including the inclusion and exclusion criteria. Methods for assessing quality and rigour in the literature were described and evidence was provided for these. A total of eight peer-reviewed research papers and one doctoral dissertation were selected for critical review. Key findings from the literature were discussed. These related to parents' experiences of educational provision for children with ASD and disabilities; parents' experiences of transition practices, and parents' experiences of the transition process. Findings from these papers suggest that the child's transition to school can be a challenging and stressful time for parents. They may struggle to find suitable school places and may have to negotiate with professionals in health and education. Some studies suggested that parents of children with ASD had similar concerns and experiences to parents of children with other disabilities (Fox et al., 2004; Lilley, 2012) while others suggested that parents of children with ASD reported more concern about their children's support needs

(Parsons, Lewis, et al., 2009). None of the studies in the critical review focused explicitly on eliciting parents' perspectives and experiences in an in-depth manner. This gap in the literature is one which the present study aims to address. The findings from this study will be presented in Chapter Four. In the next chapter, Chapter Three, the method will be described in detail. The design framework and research paradigm will be presented. Methodological considerations including reflexivity, ethical practice, power relations and quality will be discussed. The method of data collection and data analysis will be described.

3 METHOD

3.1 Overview of Chapter Three

In this chapter, I outline the method used to address the research questions in the present study. *Methodology* refers to the theory and justification for the methods of a research project (Carter & Little, 2007) while *method* refers to the manner in which data and analysis are produced in research. Discussion of the method in this study includes outlining the design framework in section 3.3, the research paradigm (section 3.4), and the rationale for the method employed. Section 3.5 introduces the method and my role as researcher. Reflexivity, and the manner in which it was manifest throughout the study, are discussed in section 3.6. In section 3.7, I outline the ethical considerations in the study and my attempts to put them into practice. Power relations between myself and the participants are discussed in section 3.8. Considerations relating to the quality of the research are discussed in section 3.9. In section 3.10, I describe the time line in which the study took place, the development of the interview schedule, the process whereby participants were selected and recruited, the participants themselves, and the context and location of the study. I give an account of the pilot interview and the research interviews in section 3.11. The manner in which data was transcribed is discussed in section 3.12. Section 3.13 provides a description of the data analysis. The summary of the chapter is presented in Section 3.14. I will report this chapter in the first person given the subjective and hermeneutic nature of my involvement as a researcher.

3.2 Research questions

In this study I aimed to explore the experiences of parents whose children with ASD are starting primary school. As described in Chapter One, I planned to address the following research questions:

- What are the experiences of parents whose children with ASD are starting school?

- What goals and options do parents feel they have around their child's education?
- What kinds of feelings do parents have around their child starting school?

3.3 Design framework

The following **figure 3.1** gives an outline of the stages involved in the study, including the identification of research questions in October 2011, the consideration of the underlying research paradigm, the choice of method, the data collection and analysis, and the compilation of the report.

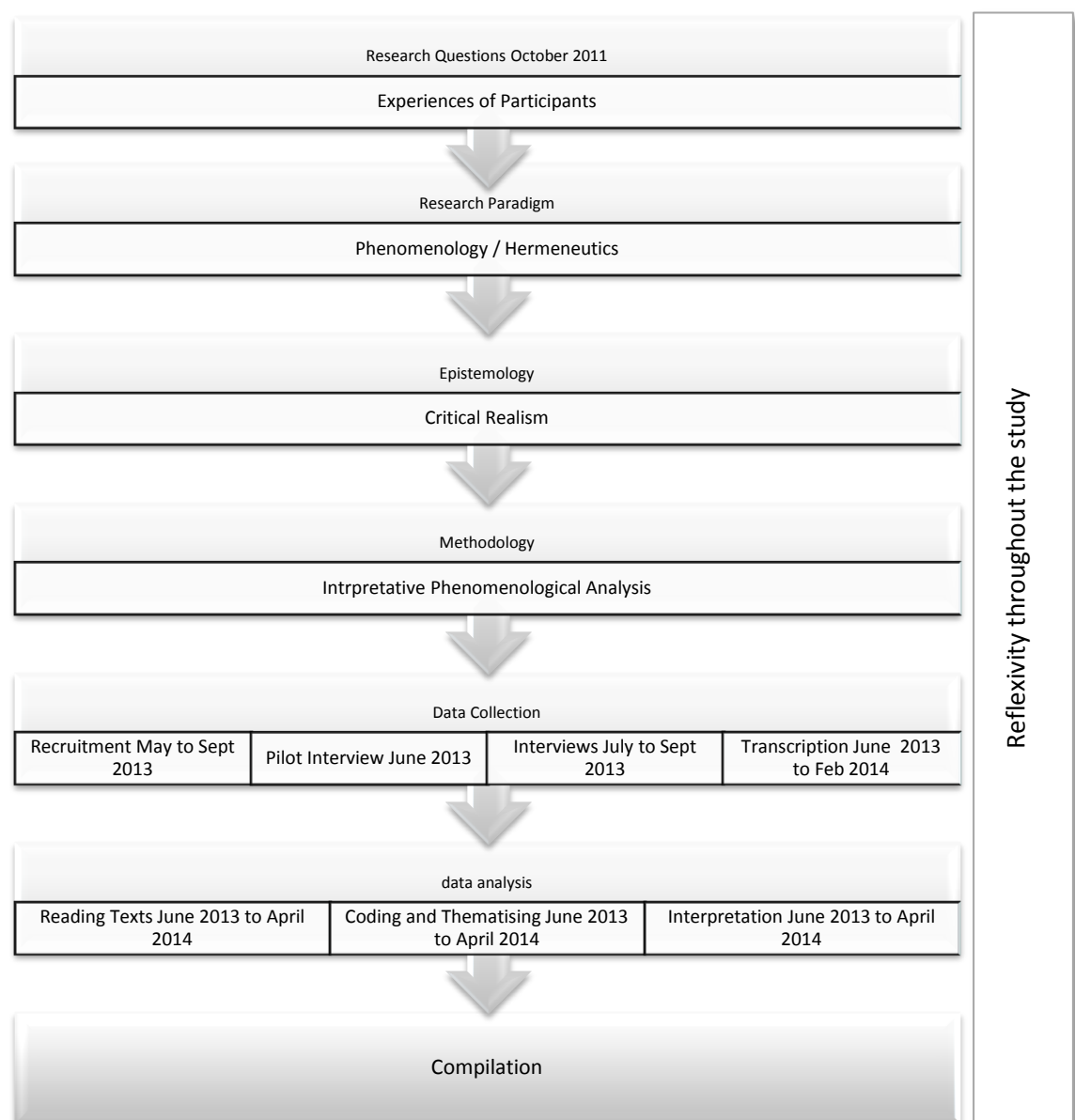


Figure 3.1 Timeline of stages in the research study

3.4 Research paradigm

The research questions in this study were aimed at eliciting participants' unique and lived experiences. Therefore, a review of philosophical approaches providing paradigmatic frameworks for the study of the person's subjective experience was undertaken. One such approach is Husserl's phenomenology (Lavery, 2003; Mertens, 2010; Smith, Flowers, & Larkin, 2009) which has its roots in the philosophical inquiry into the nature of the individual's understanding of reality; specifically, their perceptions of phenomena (experiences, objects, events). Husserl's conceptualisation focused particularly on the way in which phenomena appear through consciousness (Lavery, 2003); the key argument being that every experience should be given a careful examination to identify its essential qualities (Smith et al., 2009). Phenomenological approaches focus on the individual's meaning-making and interpretation of events in their own lives (Mertens, 2009) and are primarily descriptive (Lavery, 2003).

Heidegger, another notable philosopher in this field, worked with Husserl and was influenced by his philosophical arguments, but added to them concepts which reflected his beliefs that our meaning-making influences how phenomena in the world appear to us. His notion of Dasein (Lavery, 2003; Smith et al., 2009) referred to the person's situatedness in the world. In Heidegger's formulation, a person was rooted in their historical and cultural milieu and this impacted on how they perceived things in the world: "Because the Dasein is historical in its own existence, possibilities of access and modes of interpretation of beings are themselves diverse, varying in different historical circumstances" (Hofstadter, 1988, p. 22). Heidegger's hermeneutics, the interpretative role that individuals had in their perception of phenomena, has influenced researchers who see people as making sense of their own perceptions (Breakwell & Rose, 2006). In the hermeneutic tradition, it is assumed that people have fore-knowledge of, or assumptions about, phenomena and interpretation is seen as critical to understanding (Lavery, 2003). In this study, it is parents' own sense-making of events in their lives that is the subject of enquiry.

3.4.1 Epistemological stance

Critical realism is a philosophical theory of science proposed by Bhaskar (Bhaskar, 2008) who suggested that the pursuit of science was a combination of objective and subjective elements. That is to say, there were basic and fundamental facts and features which existed independently in the world but our approach to examining them was a socially mediated activity. Maxwell (2012) viewed the critical realist approach as fusing ontological realism with epistemological relativism. A critical realist stance can provide the underlying epistemological framework for phenomenological approaches, acknowledging as it does the part real, part constructed nature of the perceived world (Mertens, 2010). In the act of asking questions about people's experiences, one is assuming that there are experiences or phenomena to be elicited (ontological realism) and that these can be accessed and interpreted in a number of ways (epistemological relativism).

3.5 Method

According to Osborne (1994) the research question should dictate the choice of method and the researcher needs to take care that their method matches the theory they invoke. In the case of this study, which is exploratory and concerned with an examination of the person's life world, a qualitative approach was considered the most appropriate. Two methods were considered for the analysis of data in this study. The first method, thematic analysis (TA), is a commonly used means of analysing qualitative data which is not aligned to any particular epistemology or methodology (Vaismoradi, Turunen, & Bondas, 2013). It involves a six-step approach where transcribed data is analysed and coded to identify themes within a data corpus or set (Braun & Clarke, 2006). A theme might be described as a recurring pattern that captures an important essence in relation to the research question. Steps in analysis include familiarisation with the data, generation of initial codes, searching for themes, reviewing of themes, refining and naming themes, and final analysis/ write up. While TA is considered a flexible and useful approach (Braun & Clarke, 2006) some commentators would describe it as more suitable for research in which a relatively low level of interpretation is required, in contrast to approaches in which a higher level of interpretive complexity is required, such as in

phenomenological research (Vaismoradi et al., 2013). In order to adopt a rigorous analysis in line with the theoretical and epistemological stance in the present study, another method, Interpretative Phenomenological Analysis (IPA), was selected. IPA is aligned to the theoretical and epistemological paradigms in the current study and fit the purposes of the study, namely the in-depth exploration of participants' meaning making. The following section provides an overview of IPA.

3.5.1 Interpretative Phenomenological Analysis

"IPA is a qualitative research approach committed to the examination of how people make sense of their major life experiences" (Smith et al., 2009). Theoretically influenced by philosophers such as Husserl, Heidegger, Merleau-Ponty, Sartre, Schleirmacher and Gadamer, IPA combines phenomenological with hermeneutic insights (Smith et al., 2009), and examines how individuals actively make sense of the objects, people, and events in their lives (Smith & Eatough, 2006). The underlying methodological stance is interpretative and idiographic (Smith & Eatough, 2006).

IPA is inductive and "allows authors to discuss their analysis in the light of varied existing psychological theories, models or approaches" (Brocki & Wearden, 2006, p. 96). Smith and Eatough (2006) saw IPA as located within the discipline of psychology; cognition was seen as a central concern (Brocki & Wearden, 2006; Smith & Eatough, 2006). It is a method which can link "existential-phenomenological research with the wider research literature in psychology" (Shinebourne, 2011, p. 17) and fits in with the critical realist epistemological framework (Fade, 2004). In IPA, the role of the researcher is made explicit (Shinebourne, 2011) through the process of the *double hermeneutic*, where the researcher documents their process of making sense of the participants' sense-making.

IPA studies typically involve conducting individual interviews with small sample sizes or single case studies. Interviews can be semi-structured or unstructured depending on the level of experience of the interviewer. IPA analysis involves a detailed exploration of the interview text to determine how the participant constructs their meaning of the phenomena under review. The approach emphasises an in-depth exploration of each individual's experience

and a commitment to doing justice to each participant's account (Smith & Eatough, 2006). The researcher can also look for areas of convergence or divergence across cases to explore how meaning is constructed for both individuals and groups.

IPA has been used to explore such topics as the meaning that raising a child with ASD has for parents (Jardine, 2008) and to access the experiences of parents of children with ASD who have just started primary school (Miles, 2012).

3.5.2 Role of the researcher

The main purpose of an interview study is to produce knowledge; the role of the researcher as a person with integrity is critical to the quality of the knowledge produced and the ethics employed (Kvale & Brinkmann, 2009). Smith et al. (2009) listed some of the underlying qualities required of the IPA researcher as being "open-mindedness; flexibility; patience; empathy, and the willingness to enter into, and respond to, the participant's world" (p.55). The interviewer's role in a semi-structured interview is to facilitate and guide, rather than dictate exactly what will happen during the encounter.

Kvale and Brinkmann (2009) proposed that the role of the researcher in an interview study can be envisaged as that of a miner or a traveller depending on the epistemology of the study. A miner is involved in the "unearthing of preexisting meaning nuggets from the depths of the respondent" (p. 18) while the traveller "walks along with the local inhabitants" (p. 48) gathering the stories they have to tell. These two approaches represent different perspectives towards gaining interview knowledge, for example, in the mining metaphor, the aim is to extract data at the collection site (interview) and data collection is clearly separated from data analysis. In the traveller metaphor, interviewing and analysis are intertwined; knowledge is constructed and the outcome is the participants' story.

The researcher has an active role in an IPA study (Smith & Osborn, 2003). Their interpretative role is made explicit in IPA's hermeneutic aspect (Shinebourne, 2011). Willig (2012) described interpretation as being "in its most basic sense, the construction of meaning" (p. 4). At times, we are unaware that we are interpreting and, at other times, it is a conscious, deliberate activity

(Willig, 2012). The researcher uses the double hermeneutic to be explicit about their interpretation process and their role in making sense of how participants are making sense of their world.

According to Smith and Osborn (2003), different interpretative stances are possible and “IPA combines an empathic hermeneutics with a questioning hermeneutics” (p.53). IPA research aims to render an empathic account of what certain experiences are like from the participant’s point of view while at the same time, an IPA study might involve critically interpreting what participants have said to gain a deeper understanding of different phenomena.

Willig (2012) discriminated between suspicious and empathic interpretation and talked about the need for researchers to think about the status of interpretation in their research. Suspicious interpretation refers to a process whereby the interpreter assumes that true meaning is beneath the surface of what is presented and requires a deeper analysis to discover this more significant, latent meaning. The practice of psychoanalysis was used as an example. In psychoanalysis, the analyst assumes an expert role and operates under the premise that they can reveal the hidden psychic processes underlying the client’s presenting symptoms. Willig (2012) pointed out that such interpretation is theory driven, as the interpreter uses concepts and assumptions about psychological processes which impact on their interpretation of findings. Empathic interpretation is the process whereby the interpreter doesn’t assume prior knowledge about the meaning of what is presented. The interpreter aims to elaborate on the meaning and make it manifest. Empathic interpretations are grounded in the data and are not intended to be theory-driven (Willig, 2012). Whatever method of interpretation is employed, researchers should adopt a particular epistemological position in relation to the manner in which they interrogate data.

Husserl maintained that an individual could bracket their assumptions to access the pure phenomenon under examination, while Heidegger maintained that people interpret phenomena within the framework of their history and assumptions (Laverty, 2003). The researcher in an IPA study acknowledges the expert status of the participant and tries to bracket their own assumptions and hypotheses when entering into interpretation (Smith et al., 2009). To assist in the process of reflection and interpretation, researchers often keep a reflective

journal or log (Laverty, 2003). In this way, they attempt to acknowledge and examine their own assumptions so they can put them to one side while focusing on the participant's story.

3.5.3 *My role as researcher*

In this study, my role involved finding out about people's experiences of their children starting school. I took an empathic stance in that I wanted to hear what people had to say, trying to be aware of, and trying to put aside my own preconceptions and assumptions. I would identify with the Kvale and Brinkmann's (2009) miner metaphor, in that I feel I approached knowledge in this study as pre-existing. I sought to find out about people's (pre-existing) experiences and attempt to explore these experiences as factual phenomena in their own right.

In looking at my own integrity as a researcher in this study, I was conscious of being a novice researcher and of needing to find a balance between being a researcher and a practitioner as I felt there was a risk that the boundaries between those roles could be blurred. I was conscious from the outset of the data collection about the impact my role might have on my interpretation because of my familiarity with aspects of the subject area and with the types of experiences some parents might have had in similar situations.

I decided that interviewing people I didn't know might help me to remain at a greater distance emotionally from participants, thereby helping me to keep the roles of practitioner and researcher as separate as possible. To minimise subjectivity and to facilitate my learning, I sought supervision and support, recorded my impressions and referred back to them in my reflexive log, and attempted to keep track of issues and developments to inform my research practice and record any subjectivity (please refer to Appendix 12 for sample of reflexive log).

I felt there could also be advantages to my familiarity with the area and issues at the heart of this study. I have a good knowledge of the concerns that some parents have as I support children with ASD and their parents around the process of starting school in my work. I felt this may have enabled me to have a heightened sensitivity to the subject matter and the feelings of participants. This

made some aspects of interviewing easier as I felt reasonably comfortable discussing the subject matter.

3.6 Reflexivity

Reflexivity in qualitative research can be described as “disciplined self-reflection” (Wilkinson, 1988, p.493) and refers to the examination of the way in which one’s own values and assumptions shape one’s research. In being self-reflexive, the researcher acknowledges their role(s) in the research process, from the construction of the research “problem” to the reporting of the research findings; the researcher is consciously aware of their involvement and thinks through the implications of this for their research (Pillow, 2003).

Unger, Draper, and Pendergrass (1986) placed the researcher’s perspectives and beliefs in the framework of a personal epistemology, which they see as a mechanism whereby past experiences influence present judgements. They found, in a study of the worldviews of psychology students, that individuals appear to selectively expose themselves to information and knowledge that is consonant with their personal, pre-existing ideologies and that people may not often be aware of the extent to which they construct the reality with which they deal. An acknowledgement of the researcher’s particular perspectives and interests can assist the researcher to be clear about their role (Brocki & Wearden, 2006).

Wilkinson (1988) described two aspects of reflexivity which are closely interlinked; personal and functional reflexivity. Personal reflexivity refers to examination of the researcher’s identity; interests, and values, while functional reflexivity refers to examination of the nature and function of the research. Wilkinson (1988) suggested that researchers should “acknowledge the continuity between the psychological processes of researcher and researched, and to accept that they are necessarily engaged as participants in the same enterprise – a dialogue of knowledge construction” (p.495). Wilkinson (1988) also talked about disciplinary reflexivity, whereby a discipline such as psychology is required to “explain its own form and influence” (p.495); this might entail being aware of the influence of prevailing paradigms such as post-positivism on the way knowledge is constructed. Kuhn (1962) talked about the influence of textbooks and scientific writing on the development and

maintenance of paradigms in science. Much of what we learn in different disciplines and many of our professional assumptions are based on the knowledge constructed within the prevailing disciplinary paradigms.

Alvesson and Skoldberg (2009) maintained that reflective research has two fundamental characteristics, careful interpretation and reflection. They held that all references to data are interpretative acts and are influenced by the researcher's theoretical assumptions and language, among other characteristics. Interpretation should be undertaken with an awareness that it is just that, an act of interpretation; the researcher should reflect on their own personal position as an individual; as a member of a research community; society, and culture.

According to Pillow (2003), reflexivity "has been posited and accepted as a method qualitative researchers can and should use to both explore and expose the politics of representation" (p. 176). Reflexive practice has been used to address questions such as whether we can ever truly represent another person's perspective, and who's story is represented in qualitative research, that of the researcher or the participant?

Pillow (2003) talked about four reflexive strategies, commonly used in qualitative research, namely, reflexivity as recognition of self, reflexivity as recognition of other, reflexivity as truth, and reflexivity as transcendence. These strategies represent how the researcher uses self-reflection as a form of confession which "often yields a catharsis of self-awareness for the researcher, which provides a cure for the problem of doing representation" (p. 181). The process of reflexivity is used to demonstrate the researcher's awareness of problems in research and by addressing issues in research, attempts are made to validate and legitimise the research (Pillow, 2003).

However, a reliance on reflexivity as a means of validating qualitative research may work against the researcher's ethos by reflecting and reproducing the precise hegemonic structures that they strive to escape (Pillow, 2003). Therefore, she advocated a reflexivity of discomfort, wherein the researcher engages in an on-going critique that challenges how they represent their findings while acknowledging the "political need to represent and find meaning" (p. 192). The reflexive account can be viewed as one of many versions of the processes and experiences that occurred during the research and can be

analysed for the constructions that make it meaningful (Riley, Schouten, & Cahill, 2003). Therefore, the reflexive log can be used to explore new and deeper ways of understanding the research and such elements as power relations within it.

Kvale and Brinkmann (2009) outlined seven stages in a research study, namely, thematizing, designing, interviewing, transcribing, analyzing, verifying and reporting. In order to adopt a reflexive stance, I have attempted to be reflexive at each stage in this study. In the following sections, I describe how I attempted to do this.

3.6.1 *Reflexivity in thematizing*

In picking the research questions in this study, I acted from assumptions I had about what the participants might possibly have experienced, for example, they may have had negative experiences and they may have experienced worry and stress about their children starting school. I tried to be aware of my assumptions and my theories and I tried to put them to one side by considering that each person will have their own specific story to tell and their experiences may not be what I expect. I planned to listen carefully to what people had to say and to stay close to the text in interpretation.

3.6.2 *Reflexivity in sampling*

I was conscious about my role as a practitioner and how this might impact on my role as a researcher as mentioned above. I chose participants with whom I was not familiar as I felt that I would be more emotionally distant and true to the goals of the research, which was to examine *their* experiences. Furthermore, I felt that having distance between myself and participants would minimise the risk of an interview taking on a therapeutic format.

I was very conscious of not wanting to burden participants with my research and so was very tentative about recruiting people to begin with. I consulted with my supervisors around any difficulties I had or in relation to any issues that arose, for example, I sought advice on recruitment when I found it difficult to find participants. My supervisors made some suggestions, namely that I should contact people and give them the choice of participation and a

chance to say no; they raised the possibility that some people might want to contribute to the research. I then redoubled my efforts to approach people and had others approach them on my behalf and I believe that the people who subsequently participated were happy to do so.

3.6.3 Reflexivity in interviewing

Smith et al. (2009) recommended attentive listening during an interview; during the interview phase the researcher is leaving their research world and coming around the hermeneutic circle to the participant's world. Focusing on the participants' words may allow bracketing of pre-existing concerns and fore-knowledge.

A pilot interview was conducted which helped me to evaluate the research questions and my own style of interviewing. I found it difficult at times to remain neutral as a researcher and there were times where I said things that reflected a more therapeutic role as evidenced in the following extract:

We can be very focussed on the child, and thinking about these things and sometimes we forget what is important as well for parents, do you know? (Catherine and Tony, P.31, L.1050).

I noted these times in my reflexive log and made efforts in subsequent interviews to be more aware of this conflict in my roles and to try to remember I was interviewing people in the role of researcher.

In my reflexive log, I recorded my experiences as soon as possible following each interview. This included my impressions, my thoughts, and my reactions; whether I thought the interview went well and what I could have done differently. I sought advice from my supervisors when I thought an interview had been short (under 40 minutes) and I sent a transcript of the interview to a supervisor for her opinion and advice. I was reassured that even though an interview was shorter than I anticipated, I had gained sufficient data for analysis.

I encountered an ethical dilemma during Catherine and Tony's interview. During their interview, Catherine's worry and distress about Chloe's noise sensitivity became very evident. Being considerate of the intensity of their feelings and Catherine's distress, I told them during the interview that I would

discuss their concerns at the end. During the debriefing afterwards, I asked Catherine and Tony if they wanted me to communicate their concerns to Chloe's ASD team and, with their permission, I subsequently did so. This situation did not arise in other interviews but I was conscious of needing to keep the role of researcher and practitioner as separate as possible while also being open to the fact that dilemmas may arise.

3.6.4 Reflexivity in analysis

IPA is concerned with meaning. In analysing a text, the researcher is "engaging in an interpretative relationship with the manuscript" (Smith & Osborn, 2003, p. 66). Reflexivity is an important feature of the researcher's approach to interpretation and involves the researcher examining what assumptions they might have, what fore-knowledge they have, how they interpret, and what might be influencing their interpretation. It is important to bear in mind that analysis is a product of the participant and the researcher (Smith et al., 2009). A researcher in a qualitative study should be open to alternative interpretations and should be aware that interpretation might tell more about the interpreter than the participant (Willig, 2012).

As mentioned above, bracketing assumptions entails attempting to identify one's presuppositions about phenomena, so they can be set to one side in order to see the phenomena as they really are. I attempted to be aware of assumptions I had about what people's experiences might be and tried to suspend any judgements I had so that I could be open to their experiences in the analysis. I was also aware that assumptions and presuppositions are thought to frame our interpretations of phenomena in the hermeneutic tradition, so it might only be possible to explicitly acknowledge assumptions and preconceptions rather than bracketing them entirely. I was aware of the following assumptions: that sending their children to school would be worrying for parents, and that they might report issues with resources and support.

I initially found it difficult to move away from a descriptive interpretation when analysing texts and felt some guilt about interpreting what participants were saying as if to do so were to undermine their words. I was aware, however, that interpretation is a key feature of IPA so I wrote an imaginary letter to participants

to explain this and take responsibility for my interpretation and meaning-making as mentioned previously (see Appendix 4).

3.6.5 Reflexivity in reporting

According to Smith et al. (2009), the write-up is a critical part of an IPA study and the researcher needs to give an account of the data and their interpretation of it. The researcher needs to be mindful that they are distinguishing between what the participant said and their own interpretations (Smith & Osborn, 2003) and they need to be explicit about their treatment of other people's information (Willig, 2012). By presenting extracts of what participants said in the interview, the researcher is presenting the evidence for their interpretation (Smith et al., 2009). In order to be reflexive in writing up, I followed guidelines from Smith et al.'s (2009) text and based my interpretations on what people said, typing their words as accurately as I could. In some respects I kept the participants in mind in my analysis and writing as if by imagining what they might think of my treatment of their data, I would stay truer to their meanings and their intentions, for example:

That's all we want. I just don't want her coming home every day upset (yeah) and things like that so (inhales) (Tony, P.32, L.1061).

In this extract I included the inhalation Tony made at the end of the sentence as I felt it was an indicator of the salience of his emotions around Chloe starting school. Having discussed reflexivity in relation to this study, I will now describe the broader ethical considerations and principles underpinning the research.

3.7 Ethical considerations

In this section, I will describe the ethical considerations in an interpretive study and my attempts to put ethics into practice through the different stages in the project.

3.7.1 Ethical Practice

Kvale and Brinkmann (2009) maintained that ethical considerations are basic to interview research and should permeate all stages of the enquiry from the initial thematising and design to the reporting of the findings. Ethical research practice is a “dynamic process which needs to be monitored throughout data collection and analysis” (Smith et al., 2009, p. 53). This includes informing participants about what’s involved, being ethical in interviewing, and adopting an ethical stance to interpretation and writing up.

3.7.2 Ethical approval

Ethical approval was sought prior to the commencement of the study. Submissions were made to the ethics committees of services through which I recruited participants. A submission was also made to the Ethics Board of the University of East London. Recruitment commenced on receipt of approval from the relevant ethics committees. In one service where ethical approval was not required, I sent information on the research and my ethical undertakings for their information.

I fully complied with ethical guidelines in the Psychological Society of Ireland’s (PSI) Code of Professional Ethics (PSI, 2011), the PSI’s Guidelines on Confidentiality and Record-Keeping in Practice (PSI, 2011), the British Psychological Society’s (BPS) Code of Human Research Ethics (BPS, 2010), and the University of East London’s (UEL) Code of Good Practice in Research (UEL, 2010) (please refer to Appendix 5 for the ethical approval form).

The nature of the study and any possible risks were fully explained to intending participants verbally and in written format. Participants were informed that they were in no way obliged to volunteer if there was any personal reason (which they were under no obligation to divulge) why they should not participate in the study. They were also informed that they were entitled to withdraw from the study at any time during data collection, without disadvantage to themselves and without being obliged to give any reason. They were assured that personal data would be treated confidentially.

3.7.3 *Ethics in interviewing*

Texts on the subject of conducting interviews were consulted to ensure best practice. Smith et al. (2009) talked about avoidance of harm and the need to be sensitive to the manner in which talking about particular issues might constitute 'harm' to the participant.

Efforts were made to ensure the comfort of participants, for example, they were interviewed in their own homes and at times that suited them. I made a conscious effort to adopt a respectful but relaxed and informal manner. After each interview, I made time to allow participants to discuss anything of concern arising from the interview. In actual fact, none of the participants appeared distressed following our interviews.

3.7.4 *Ethics in interpretation*

The act of interpretation involves a "degree of appropriation" (Willig, 2012, p. 19) and so there is a need to think about one's epistemological position when using interpretation, for example, is the researcher employing suspicious or empathic interpretation, or a mixture of both? Willig (2012) maintained that researchers need to ensure they have the training and awareness to engage in interpretation. Furthermore, researchers shouldn't claim to know what the participant's account really means. Being ethical in interpretation involves transparency in methodology, for example, showing how the data leads to the claims about knowledge. Willig (2012) also talked about "paying attention to the relationship between the data and the claims that are made in the interpretation of it" (p. 155). As mentioned previously, I attempted to be explicit about my role in interpretation and the findings in this study represent my interpretation of what I believed participants' said.

3.8 Power relations

The interview in a research study can be seen as being "a specific professional conversation with a clear power asymmetry between the researcher and the subject" (Kvale & Brinkmann, 2009, p. 33). There are a number of reasons for this: the interview is set by the interviewer with a one-directional focus on eliciting information from the participant. It is a purposeful dialogue which may

have a hidden agenda and one in which the interviewer has a “monopoly of interpretation” (Kvale & Brinkmann, 2009, p. 34).

The interpreter has the “power to shape” (Willig, 2012, p. 19) and such power carries the risk of being abusive. Interpretation raises questions relating to ethics such as who owns the information and how does the interpreter shape the information? What happens if the informant doesn’t recognise their information in the interpretation? Interpretation may say more about the interpreter than the informant and so there is a need for the researcher to be reflexive. Wilkinson (1988) held that the power of the researcher and the researched is not equivalent and the researcher has the main influence in all aspects of the research domain.

Teo (2010) talked about epistemological violence where the research produces *knowledge* which problematizes or stigmatises the participant or group of participants. He recommended that researchers reflect on their own biases and intuitions when conducting research because of the influence their interpretations can have on how participants are viewed by others.

As interviewer I was conscious of a further possible imbalance in the power relations between me and participants. I felt that they might have expectations of me as a psychologist working in services; that I might be seen in my professional role rather than my role as a researcher. I made a conscious effort to emphasise the importance of the research and the importance of what participants had to say rather than refer to my “day job” as a psychologist.

3.9 Quality

Discussions around quality in qualitative research have been prompted by dissatisfaction in the research community with the manner in which qualitative research has been assessed and evaluated using criteria best suited to quantitative methods, which may not be appropriate (Smith et al., 2009). Positivistic criteria do not accord with the underlying ontology and epistemology of interpretive research methods (Sandberg, 2005) and so do not reflect the constructivist aspects of many qualitative methods.

Yardley (2000) offered four principles for assessing the quality of qualitative research which are discussed below. These include sensitivity to context; commitment and rigour; transparency and coherence, and impact and

importance. I have tried throughout the study to keep these principles in mind as yardsticks by which to measure the quality of the research.

3.9.1 *Sensitivity to context*

Being sensitive to context can refer to awareness of the theories and research literature surrounding topics under examination; in a qualitative study this would entail having knowledge of the philosophical basis of the approach undertaken as well as the different perspectives and arguments surrounding the topic under examination. The social context between researcher and participant is very important; therefore, Yardley (2000) recommended reflexivity around the researcher's actions and characteristics. It is considered necessary to be aware of the balance of power between researcher and participants in the study.

Smith et al. (2009) contended that IPA researchers demonstrate sensitivity to context in their choice of IPA as a method, concerned as it is with the idiographic and the particular context of the participant.

3.9.2 *Commitment and rigour*

Commitment, in Yardley's conceptualisation, refers to the researcher's engagement with the topic and method used as well as their competence and skill in using the method. Rigour refers to the quality of the data collection and analysis. In interpretative methods, this refers to the quality, completeness and complexity of the interpretation.

According to Smith et al. (2009), commitment is demonstrated in an IPA study through attentiveness to the participant in the interview, and through the care that is given to analysing the data; rigour is demonstrated throughout the process through such activities as the thought put into the selection of participants, the quality of the interview, the thoroughness with which analysis is undertaken, and the selection of codes and themes.

3.9.3 *Transparency and coherence*

Yardley (2000) proposed that transparency and coherence are important factors in how qualitative research is presented. The narrative should be clear, convincing and meaningful to readers. This can include how data and analysis

are presented and described, and the degree to which all relevant aspects of the research process are detailed. Reflexive practice can be used to explicitly acknowledge the researcher's assumptions and to explain the researcher's actions.

A researcher in an IPA study demonstrates transparency by carefully describing the different stages in the study, from selection to analysis and writing up (Smith et al., 2009). Furthermore, the IPA researcher attempts to provide a coherent account of how the study was conducted; how the resulting themes fit together as well as to support the final arguments.

Smith et al. (2009) talked about the critical role that the reader has within the "hermeneutic dialogue" (p. 109) in that the reader must be able to make sense of the researcher's sense-making of the participant's lived experience.

3.9.4 *Impact and importance*

Yardley (2000) considered impact and importance / utility to be decisive criteria by which any research is judged. She argued that qualitative research needs to have both theoretical and practical impact (Yardley, 2000). This can happen, for example, in action emancipatory research studies.

Smith et al. (2009) maintained that the IPA researcher should be aiming to tell the reader something "interesting, important or useful" (p. 183).

3.9.5 *Validity*

According to Sandberg (2005), within interpretative approaches, the human world is an experienced world. For this reason, the underlying epistemological and ontological assumptions reflect a rejection of the idea of an "objective, knowable reality beyond the human mind" (p. 43). Positivistic criteria for measuring validity and objectivity are therefore inappropriate. However, Smith et al. (2009) recommended that qualitative researchers take issues of validity and quality seriously.

Kvale and Brinkmann (2009) proposed that instead of rejecting concepts of reliability and validity, they could be reconceptualised in terms which are relevant to interview research. Reliability could be viewed as the consistency and trustworthiness of the researcher's methods and of the findings.

Validity is conceptualised as the degree to which “a method investigates what it is intended to investigate” (Kvale & Brinkmann, 2009, p. 246), and in principle, qualitative research can lead to scientific knowledge. Validity can be seen to permeate the research process, from the design and thematizing to the reporting. Furthermore, the researcher’s expertise or *craftsmanship* and integrity is central to questions of validity (Kvale & Brinkmann, 2009).

3.9.6 Transferability

The aim of this study was to explore a phenomenon as it exists for these participants in a particular context. IPA is idiographic in nature and, while IPA research does not oppose making general claims, it is committed to analysing small numbers of cases; this may lead on to generalisations through slowly building up a case by case understanding of phenomena (Smith & Osborn, 2003; Smith & Eatough, 2006).

The sample size was small and purposefully selected and for these reasons, I can make no claim to generalizability beyond the scope of the study. An IPA researcher can think in terms of theoretical rather than empirical generalizability: “Theoretical propositions can be refined and modified through comparison with other cases, other conceptual claims in the extant literature, and the personal and professional experience of the researcher or reader” (Smith & Eatough, 2006, p. 329).

Yardley (2000) discussed the pursuit of transferability as opposed to generalizability in qualitative studies. Transferability refers to the possibility of transferring findings from group to group so that we may, for example, gain a better understanding of a phenomenon (Hefferon & Gil-Rodriguez, 2011). I hoped that, in this study, I would perhaps be able to identify important themes common to individuals and that the experiences of individuals may give insight into the topic under investigation.

3.10 Data collection

In this section, I will outline the context and location within which the study took place; the means by which participants were selected and recruited, and a brief description of the participants is provided.

3.10.1 Context and location

The study took place in two counties in southern Ireland. Participants were parents of children with ASD who were accessing MDT support services from publicly-funded voluntary agencies.

3.10.2 Selection

Smith et al. (2009) recommended a sample size of between three and six participants for a student project as these numbers should provide enough cases for examining differences and similarities between participants' accounts but not an overwhelming amount of data. Therefore, a sample size of six participants was considered optimal for this study.

Participants were selected by purposive sampling. An attempt was made to keep the sample homogenous (all parents had children with ASD due to start primary school in September 2013) to ensure that research questions via the interview questions would be meaningful to participants (Smith et al., 2009) and that the data yielded would be relevant to the phenomena under review.

3.10.3 Inclusion criteria

Two criteria were used in the selection process, namely, that participants were parents of preschool children in receipt of services from an ASD-specific MDT support team, and that their children were starting school in September 2013.

I had initially planned to interview parents whose children would be attending a mainstream school setting, however, in between the time I had selected participants and then interviewed them, parents of two of the children had changed their choice of educational setting and the children were to attend "special" classes attached to mainstream schools. I decided that this did not change the homogeneity of the sample unduly as the children would still be attending mainstream school in some capacity; children who attend special classes have opportunities to integrate with mainstream peers during the day. Changing proposed placements is a feature of the transition process for some parents and their children as new places become available in special classes or it becomes evident that the child would benefit from a more supportive

educational environment. According to Smith and Eatough (2006), it is not unusual to have to adapt the criteria for inclusion in an IPA study.

3.10.4 Exclusion criteria

Participants were excluded on the basis of three criteria, namely that they were parents of children who were to attend special schools, that they were parents who were known to me, and that they were parents who were likely to experience potential distress.

I felt that to interview parents of children who were to attend a special school would make the sample less homogeneous as they would possibly have different experiences owing to the additional needs of their children (such as ID) and the different issues involved when a child is starting school in a very specialised setting.

3.10.5 Potential distress

I discussed potential participant distress with colleagues who supported me in recruiting participants, for example, two colleagues in service A (please see section 3.10.6) felt that a potential participant who had a recent bereavement could possibly experience undue distress in an interview. In the cases of other potential participants, we did not feel that the interviews themselves would cause distress but decided that if follow-up was needed, or if something came up in interview that caused distress, I could discuss with participants the possibility of their linking in with colleagues for support. I also offered to be available to participants after each interview if necessary. Information was given on local supports, for example, a local counselling service in the service A region. In the event, participants did not exhibit undue distress and did not contact me for support following the interviews.

3.10.6 Recruitment

In order to access participants, I made approaches to four services, which I will label A through D, providing MDT support to children with ASD and their families. Potential participants were identified based on the criteria described in the sections above.

In service A, two psychologists identified eight sets of parents who met the inclusion criteria. I sent one of the psychologists information packs for potential participants which were sent to parents on my behalf. The pack included a letter of introduction (Appendix 6), a form entitled Consent to be Contacted (Appendix 7), which they could return to me in a stamped, addressed envelope if they wished to be contacted, and a description of the study and what it was to involve (Appendix 8). Two parents responded, one of whom was able to participate.

In service B, the director of services identified three potential participants, two of whom agreed to be contacted. The director forwarded their phone numbers and I contacted both parents and sent them information packs. One parent was able to make time to be interviewed. The other parent, though willing, found it difficult to find a time to meet me and, having left a message by telephone, and a follow-up e-mail, I decided not to pursue the interview.

Two parents who met the inclusion criteria were identified in service C where staff approached them to ask if they would be interested in taking part. Both parents agreed to take part and in the case of one parent, her partner became the fifth participant.

In the case of the last participant to be interviewed, I contacted a voluntary service for families of children with ASD (Service D) and they identified a mother who contacted me three weeks after her child had started school. In the case of this participant, I contacted my supervisor for advice as the little boy had just started school, unlike the other children whose parents had been interviewed prior to starting school. Following a discussion, we agreed that three weeks was within the transition timeframe and so the participant was included in the study.

All participants signed consent forms (please refer to Appendix 9) agreeing to participate. Participants were given written and verbal information about the study, including what was involved for them, what would happen to their data and the possible outcomes of the study, namely compilation into a report and possible publication. I explained about confidentiality and anonymity and the care I would take in storing data. Parents were given a debriefing sheet with information about support available should they experience distress following

the interview (Please refer to Appendix 10). All participants were invited to contact me should they need to do so.

3.10.7 Participants

As mentioned above, participants comprised six parents whose children with ASD started school in September 2013. Five mothers and a father were interviewed for the purposes of this study. All of the children who were starting school had a diagnosis of ASD and were receiving support from services providing multidisciplinary therapies such as speech and language therapy, occupational therapy, psychology, and social work.

These participants represent a small population of people who could be identified and did not want to be identified; therefore I have changed their names and the names of their children and will give brief details about them to protect their anonymity. Maria has two children with ASD. We spoke about her younger child, Paul, who was starting mainstream school and references were also made to her older child's experiences of starting school some years previously. Maeve has a number of children, two of whom have ASD. Her younger boy, David, was due to attend a special class, and reference was also made to her older child's experiences. Tony and Catherine's little girl, Chloe, was starting special class in a mainstream primary school. Olivia is the mother of a little boy, Cormac, who was due to attend a mainstream class. Hannah has two children with ASD. We spoke about her younger son, James, who was starting in a mainstream school. Reference was also made to her experiences with her older son. Table 3.1 gives an outline of the participants in the study; the proposed type of school placement, and the presence of a sibling with ASD.

Table 3.1 Parents and children with ASD starting school, school placement and sibling with ASD

Parent(s)	Child	Proposed type of school placement	Sibling with ASD
Maria	Paul	Mainstream class	Older brother
Maeve	David	Special class	Older brother
Tony and Catherine	Chloe	Special class	None
Olivia	Cormac	Mainstream class	None
Hannah	James	Mainstream class	Older brother

It is notable that three of the participants had two children with ASD. This may raise questions about the homogeneity of the sample. These participants were interviewed in relation to their younger child with ASD but had previous experience of sending a child with ASD to school and so differed from the three other participants for whom it was their first time sending a child with ASD to school. In the analysis and interpretation, I was mindful of the impact of having an older child with ASD on the participants' current experiences.

3.11 The interviews

In this section, I will give an account of the process whereby interviews were initially conceptualised and then realised.

3.11.1 Interview dynamic

Kvale and Brinkmann (2009) proposed that an interview question has both a thematic element and a dynamic element. Thematically, the question aims to produce knowledge. There is a balance between spontaneity and structure as the researcher aims to encourage the discussion of perhaps unexpected and new information, while also trying to keep a coherent account which will lead to later conceptual clarity in analysis. The dynamic element relates to a question's ability to promote a good reaction on the part of the participant; this means that questions should be designed to promote a good rapport and allow people to talk openly about their opinions, feelings and experiences. In the section below, I describe how I developed the interview script.

3.11.2 Interview script

Primary research questions in an IPA study should be open and exploratory as opposed to closed and explanatory (Smith et al., 2009). They should direct the researcher towards an exploration of meaning. Constructing an interview schedule is advised so that the researcher can focus on the areas under examination and can anticipate any difficulties that may arise (Smith & Osborn, 2003). This allows for the inclusion of key questions to guide the interview but the flexibility to move away from a script if other interesting questions arise. By

keeping flexibility, the participant is given maximum opportunities to tell their own story (Smith & Osborn, 2003). This provides an interpretative facet to the data generation (Brocki & Wearden, 2006) as the researcher thinks about what and how to ask questions in the context of the interview. A number of types of interview questions which can enhance an in-depth interview are described by Smith et al. (2009). These include questions which encourage description, narrative accounts, evaluation, comparisons, and contrasts. Prompts and probes are used to allow a more thorough exploration. The first question should be one that allows the participant to describe an event or experience, allowing them to become comfortable.

A semi-structured interview script was devised (see Appendix 11) as recommended by Smith and Osborn (2003), who maintained that this was probably the best way to conduct an IPA interview. Questions were open and expansive (Smith et al., 2009) and were expressed in the everyday language of the interviewee (Kvale & Brinkmann, 2009). I gave these to an expert panel to review, namely two psychologists in the service where I work and my academic supervisors. On receiving feedback, I realised that my initial schedule was too close to the research questions and was not particularly naturalistic or inviting of rapport. I amended the schedule to be more naturalistic and open. I familiarised myself with the script so that I wouldn't need to refer to it during the interviews as this might interrupt the flow of conversation and impact on rapport.

3.11.3 Pilot interview

To ensure the suitability of questions and my own interviewing technique, I conducted a pilot interview with a participant who was known to me and whose child with ASD was starting school in September 2013. She gave me feedback on the interview which was positive. I felt that the schedule had allowed me to access her experiences around her own child starting school. I felt that she had opportunities within the interview to spontaneously share and add information about her experiences which were relevant to the study. I did not use this data in the research study as it was used to hone my technique and interview questions.

3.11.4 Research interviews

I conducted four individual interviews and a double interview with two parents together in line with their wishes. An audio recording was made of each interview using digital recording equipment. I gave each participant a consent form to sign and explained the nature of the interview. Written information was given to each participant.

An interview is a conversation with a structure (Kvale & Brinkmann, 2009) and a purpose (Kvale & Brinkmann, 2009; Smith et al., 2009). With this in mind, I adopted a conversational, more than a questioning tone, allowing people the space to tell their story. As mentioned above, I made every effort to ensure that I had an informal and relaxed attitude to help put participants at ease. I undertook to allow participants speak and interrupted to ask direct questions or clarify around a particular feeling or experience. I watched for any sign of distress that my questioning could cause.

Three interviews took just over an hour and two interviews took just under forty minutes. I feel this was due to the participants' own conversational and interactional styles. **Some participants were more succinct in their answering** and were less inclined to elaborate on questions about their feelings. I was mindful of not wanting to put undue pressure on participants to share painful feelings as this might cause distress and would not be ethical.

After each interview, there was time for debriefing where I thanked participants and asked them if they were okay, if they had any feedback or questions for me, or if they had anything else they wished to discuss.

3.12 Transcription

In this section, I will describe the processes whereby the research interviews were transcribed. This will include theoretical and methodological considerations and reflexivity.

3.12.1 Theoretical considerations in transcription

According to Davidson (2009), there is a growing recognition in the research literature of the need for researchers to be explicit about the manner in which they use transcription. This would include being explicit about the researcher's

theoretical assumptions, their choice of particular transcription methods, the relevance of the analysis, steps taken to ensure validity, and quality and the acknowledgement that the transcript only gives a partial account of what happened in the interview.

Kvale and Brinkmann (2009) considered that transcription is not merely a clerical process but is also an interpretative process where the conversational interaction becomes abstract and fixed. The transcripts become the empirical basis of the research study. Transcriptions are the researcher's data and what they contain will "influence and constrain what generalizations will emerge" (Ochs, 1979, p. 45).

The researcher needs to bear in mind that the oral form is transformed into written form in the act of transcription and this produces "hybrid, artificial constructs that may be adequate to neither the lived oral conversation nor the formal style of written texts" (Kvale & Brinkmann, 2009, p. 178). Certain intentions of the participant, such as humour or irony, may be lost in translation (Kvale & Brinkmann, 2009).

3.12.2 Method of transcription

Interviews in IPA studies are usually transcribed verbatim and include questions and comments made by the interviewer (Smith & Osborn, 2008) and therefore, interviews should be recorded. Smith et al. (2009) suggested that an IPA transcript would not require a detailed transcription of prosodic aspects as IPA is more concerned with semantic aspects.

In this study, the digital audio recordings of each interview were transcribed verbatim and word-by-word using a word processor. Data were typed onto a page with three columns. The column on the left hand side was blank for note-making and coding, the middle column had numbered lines and the column on the right contained the text. A space was left between each turn in the conversation. To provide more visual clarity in the lengthy texts, I accorded each speaker a different coloured background, for example, white for the participant and blue for myself.

I included features of speech such as significant pauses, laughs and false starts as recommended by Smith and Osborn (2008) and any features which I thought would preserve the participants' intended meaning. **Table 3.2 below**

illustrates how prosodic speech features were recorded to enhance semantic interpretation.

Table 3.2 Notation of features of speech in transcription

Feature of speech	Description	Example
Significant pause of one to two seconds	Two colons	..
Significant pause of two plus seconds	The word pause in brackets	(pause)
False start	Hyphen	-
Laugh	Word laugh in brackets	(laugh)
Stress on a word	The word in italics	
Anonymised name or place	The designation in brackets	<school>
Short turn taken by other person	Comment in brackets inserted into speech	(okay)
Designation where words are omitted in an extract	Three colons	...

An excerpt from Maeve's interview transcript (P.1, L.8), illustrates the use of notation features:

So we've kept him back.. well, he'll be five -five and a bit – starting school (yeah) but he's very immature (okay) so this year we have to send him to ..

Shorter pauses were indicated by two colons for a pause of one to two seconds, longer pauses were indicated by the word pause in brackets; false starts were indicated by a hyphen; laughs were indicated by the word 'laugh' in brackets; commas, full-stops and question marks were used to signify the end of a sentence, the natural pause in speech, and the asking of a question respectively; anonymised locations were indicated by placing the location in angled brackets, for example <school>; words which had a significant stress in

speech were italicised; short affirmations or comments made by the other person while one person was talking were inserted in brackets. Three colons were used where I had omitted some of the speech in an extract.

3.12.3 Reflexivity in transcription

Through the process of transcription, I learned about my own interviewing style and ways in which I could improve my interview technique, for example, there were occasions when I could have asked participants to elaborate on their experiences, and, as mentioned before, there were points at which I felt I took on a role more suited to practitioner than researcher when responding to participants' accounts of painful events in their lives.

I tried to transcribe the interviews as faithfully as possible to the original conversations. I listened back to phrases and sentences a number of times to preserve the accuracy of the verbatim account. I tried to preserve some of the intended meaning by including prosodic features of speech. Transcription, however, is interpretative and different meanings can be extracted from a single text depending on how a transcriber chooses to record features of speech (Kvale & Brinkmann, 2009).

The act of transcribing someone's words has consequences and Kvale and Brinkmann (2009) recommended that researchers be aware that publishing verbatim interviews which may seem incoherent to readers "may involve an unethical stigmatisation of specific persons or groups of people" (Kvale & Brinkmann, 2009, p. 187). I feel the transcription method I adopted gave as accurate an account as I needed for an IPA study and would offer a respectful account of what participants said.

3.13 Data analysis and interpretation

In this section, I discuss theoretical considerations relating to analysis and interpretation in qualitative research and I describe the process whereby interview transcripts were analysed and interpreted.

3.13.1 Theoretical considerations in data analysis and interpretation

Willig (2012) discussed the relationship between analysis and interpretation; she noted that qualitative researchers have preferred to use the term ‘analysis’ to ‘interpretation’ as analysis implies a more scientific and systematic approach to the organising of themes. Interpretation has been associated with the humanities. For the purposes of this study, I will use the terms interchangeably because of the nature of IPA which involves both analysis and interpretation at all levels of engagement with data.

In analysing and interpreting data in this IPA study, I focused on meaning. Kvale and Brinkmann (2009) outlined ways in which a researcher can do this in an interview study, including meaning coding, meaning condensation, and meaning interpretation. Coding can be concept driven or data driven. In the former, the researcher starts with theoretical assumptions and examines the data in the context of these assumptions. In data-driven coding the researcher develops codes through their reading of the data. Data that can be coded includes behaviours, specific acts, events, activities, strategies, meanings, relationships, interactions, settings, and the researcher’s own role in the process (Taylor & Gibbs, 2010).

Meaning condensation involves making shorter formulations of what the person interviewed said. A stepped approach to meaning condensation includes reading through the entire text to get a sense of the narrative, determining natural meaning units, identification of themes, interrogation of meaning units in terms of the purpose of the study, and compiling essential themes into a descriptive statement.

Meaning interpretation involves interpreting “beyond what is directly said in the text to work out structures and relations of meanings not immediately apparent in a text” (Kvale & Brinkmann, 2009, p. 207). Questions may arise for the researcher at this level of meaning analysis, for example, they may need to make a decision about the type and level of interpretation they make (empathic or suspicious, going beyond the manifest to the meaning behind what is said). Furthermore, the researcher may need to address philosophical questions such as whether a “correct” interpretation exists, whether there is a “real” meaning behind what is being interpreted and who owns the meanings of a statement, in other words, whether one person (the interviewer) can claim that their

interpretation is the only correct one and that their interpretation captures the real meaning behind what the participant is saying or the facts of the situation.

Smith et al. (2009) maintained that there is no single, prescribed method for working with data in an IPA study. However, they outlined a set of common processes which could be applied flexibly to facilitate analysis in such a study. They proposed that the researcher can adhere to a number of key strategies beginning with a line-by-line analysis of the participant's experiences, concerns and understandings and the identification of patterns, or themes, in the text. This is followed by the development of a dialogue between the researcher, the data and the researcher's understanding of meaning for the participant, leading to the genesis of a more interpretative account. A framework which illustrates the relationships between themes can be developed and this material organised so data can be analysed and traced through the process of analysis. Supervision, collaboration or audit can be used to test and develop the validity of the interpretation. Finally, the development of a narrative account can occur which takes the reader through the themes, and provides reflection on the researcher's own conceptions and perceptions.

3.13.2 Steps in analysis

In this study, I followed the procedural guidelines proposed by Smith et al. (2009) which they detailed in a series of steps described below. Given that IPA is idiographic, they suggested that each case should be analysed in detail before moving on to the next case. I also referred to Kvale and Brinkmann (2009) where I felt suggestions they made added to the richness of the analysis, for example, being aware of the narrative process in the participant's telling of their story.

3.13.2.1 Step 1: Reading and re-reading

Before reading over the transcripts with the development of codes in mind, I read each text to try and capture the essence of the narrative. Kvale and Brinkmann (2009) differentiated between the narrative told by a participant in an interview study and the analysis of elements of their story. The participant tells a story in an interview and the transcript is an approximate final form of that story.

The researcher translates and interprets the story told by the participant and presents this interpreted version to the audience. Kvale and Brinkman (2009) maintained that there should be a focus on the interview as a narrative as this is the form it takes in the interview originally and this may make for better reading. Smith et al. (2009) suggested that the researcher might also record their recollections of the interview and their own initial observations of the transcript to 'bracket' them off for a while during this initial reading phase. Following each interview, I recorded my impressions and recollections in my reflexive log, an extract of which can be seen in figure 3.2 below (please see Appendix 12 for further samples of the reflexive log):

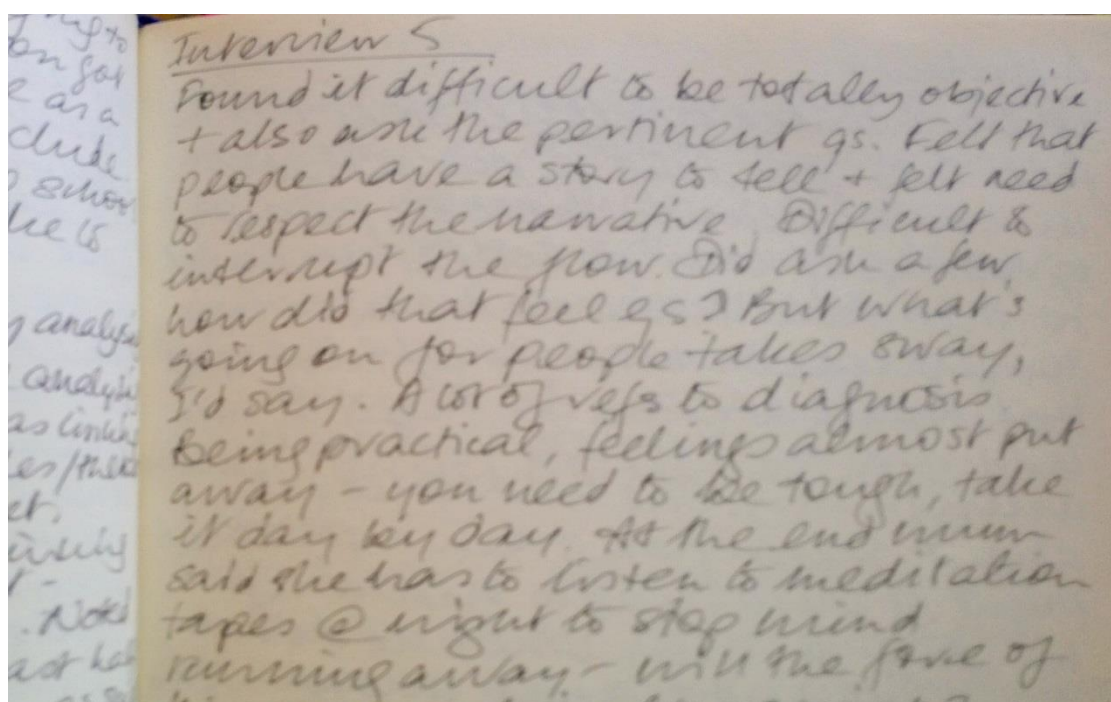


Figure 3.2 Extract from reflexive log

3.13.2.2 Step 2: Initial noting

This step involves the examination of the semantic and prosodic features of language use. In this way, the researcher grows more familiar with the transcript and aims to make comprehensive and detailed notes on the data. Comments should relate to descriptive, linguistic, and conceptual features of the text which capture details of the content of what the participant said. The manner in which the participant uses language can be described and the process of moving towards interpretation can begin. In this way the researcher engages in a

detailed examination of the transcript, allowing them to explore different avenues of meaning and to start a more interpretative engagement with the text.

In this phase, I re-read the transcripts. To adhere to the procedure for initial noting outlined by Smith et al. (2009), I used a biro and different coloured highlighter pens to underline parts of text matching each of the comment types described above. I underlined descriptive comments using a biro; descriptive comments related to significant events and people in the life of the participant. I used a blue highlighter pen to underline linguistic features which I thought interesting, for example, when Maeve said “we have to send him to <school>” (P.1, L.10), I thought the use of the phrase *have to* might be interpreted as the participant feeling under pressure to send their child to school and I checked the sense that this made within the context of the overall narrative account. I used green highlighter pen to underline a participant’s expression of their thoughts and orange highlighter pen for expressions of their feeling; the colour yellow was used to highlight conceptual elements of the text leading to the development of initial codes, and the colour pink was used to designate themes. Please refer to Appendix 13 for a sample interview transcript. An extract is provided in **figure 3.3** below:

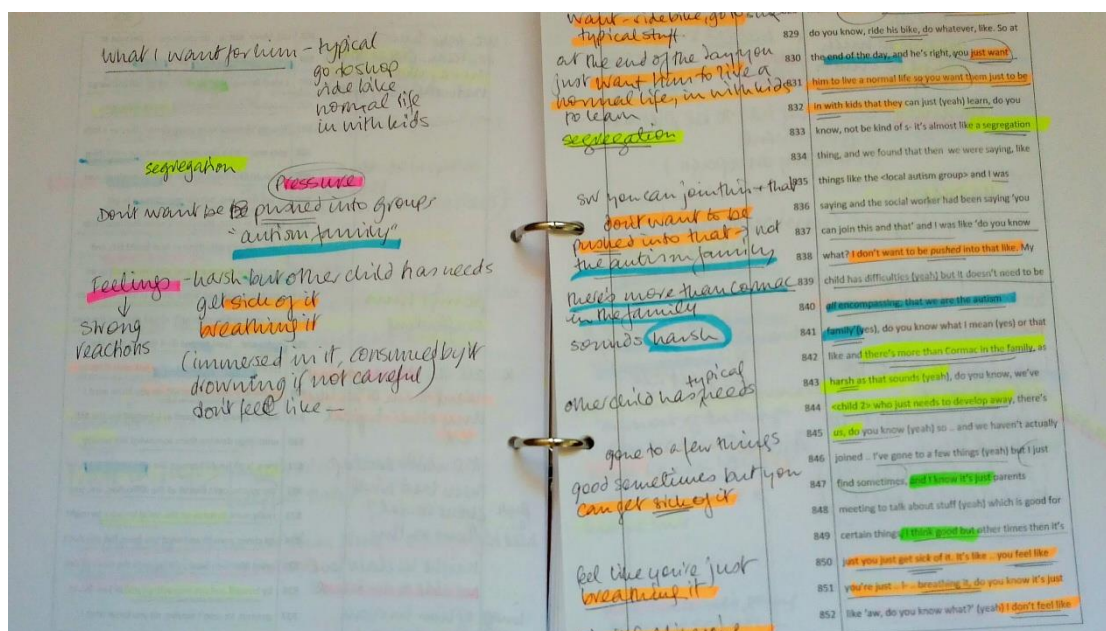


Figure 3.3 Extract from interview transcript

3.13.2.3 *Step 3: Developing emergent themes*

In this step, the researcher attempts to reduce the amount of detail in the text while retaining the complexity of the data. The researcher moves away from the text and begins to focus on their own initial notes, attempting to map the relationships, patterns and connections between the initial notes (Smith et al., 2009). The researcher focuses on both discrete pieces of the transcript and the general gist of the narrative. The hermeneutic cycle is made apparent in the process as individual parts of the transcript are examined within the context of the whole interview. The generation of themes, namely, “phrases which speak to the psychological essence of the piece” (Smith et al., 2009, p. 92), involves description and interpretation and should describe the essence and meaning in the participant’s narrative.

In the process of developing themes, I thought about what the participant intended and what the meanings behind the stories they told might be. For example, when Maria said “It’s hard to get them to understand that” (P.5 L. 131), I felt this related to difficulties she had with the school’s understanding of her situation and her child’s difficulties. In looking at this participant’s story, the theme “Understanding and being understood” reflected difficulties her child had in understanding the world; her efforts to understand the school’s perspective, and difficulties the school staff had in understanding her son. I made notes about codes in the left hand column. I recorded any impressions I had about themes that I identified on the left page (the back of the previous page of text). Please refer to figure 3.3 above.

3.13.2.4 *Step 4: Searching for connections across emergent themes*

In this step, the researcher looks at the way themes they have identified fit together by noting any similarities and differences between them. Reference is made to the original research questions. Smith et al. (2009) suggested two basic ways of looking for connections, one of which I adopted as it was recommended for novice researchers. This method involved typing out themes in chronological order and identifying those that appeared to cluster together. Smith et al. (2009) described a number of specific ways of looking for patterns and connections between themes to aid in the analytic process including abstraction, subsumption, polarization, contextualisation, numeration, function,

and bringing it all together. These processes involve the identification of patterns between themes; the identification of subordinate, and superordinate themes which could be condensed into overarching themes; the focus on differences as well as similarities within themes; the focus on the context of the narrative which frames thematic development; the noting of the frequency with evidential support for a theme arises, and the function of language use. Having followed these steps, the researcher can begin to organise a graphic representation of the themes. This can be carried out using a computer as I did in figure 3.4 below and in Appendix 14.

Text	Page / Line	Subordinate theme development Having choice Making choice	Superordinate theme Choice
We chose not to take it – silly, we were stupid but .. So we chose not to take the place Just taking these choices to see what would suit your child We made bad choices with Peter	7.151	Trying to balance needs Made wrong choice	Made wrong choice
	7.155		Having choices/
	16.396	Need to think it through	Not having choices
	17.402	Getting it wrong	Getting it wrong Hope

Figure 3.4 Extract from table of superordinate themes and themes from Maeve's interview

I recorded key words and phrases in the left-hand column and recorded the page and line number in the second column. In the third column, I recorded codes and emerging themes, and in the fourth the comments that evidenced subordinate and superordinate themes. In the sample above, the superordinate theme was "Choices for school". When I had coded all of the text in this manner and had clustered the codes into subordinate and superordinate themes, I compiled these into a table of themes. As I did so, I noticed that I made new connections between subordinate and superordinate themes, and where it made sense to do so, I re-ordered my themes. I then looked at how themes fitted together into overarching themes. Table 3.3 shows an extract from a table of Maeve's subordinate; superordinate, and overarching themes.

Table 3.3 Maeve's overarching theme '*Feelings about school and sending her children to school*'

Superordinate and subordinate themes	Overarching theme
Maeve's feelings about sending her children to school <ul style="list-style-type: none"> - (Previous experience – home versus school - trying to make the right choices 	Maeve's feelings about school and sending her children to school
Maeve's feelings about school <ul style="list-style-type: none"> - Maeve's feelings about educational options - Maeve's feelings about educational staff - Maeve's feelings about David starting school 	

This thematic representation aided the development and organisation of the individual participants' themes. I initially felt that I had too many themes so I explored using another type of graphic representation to chart the connection between themes. Figure 3.5 below is an example of a map of the overarching theme "Olivia's experiences of services, support and the system" from Olivia's transcript. The overarching theme is on the left; superordinate themes are in the middle, and subordinate themes are to the right of the figure.

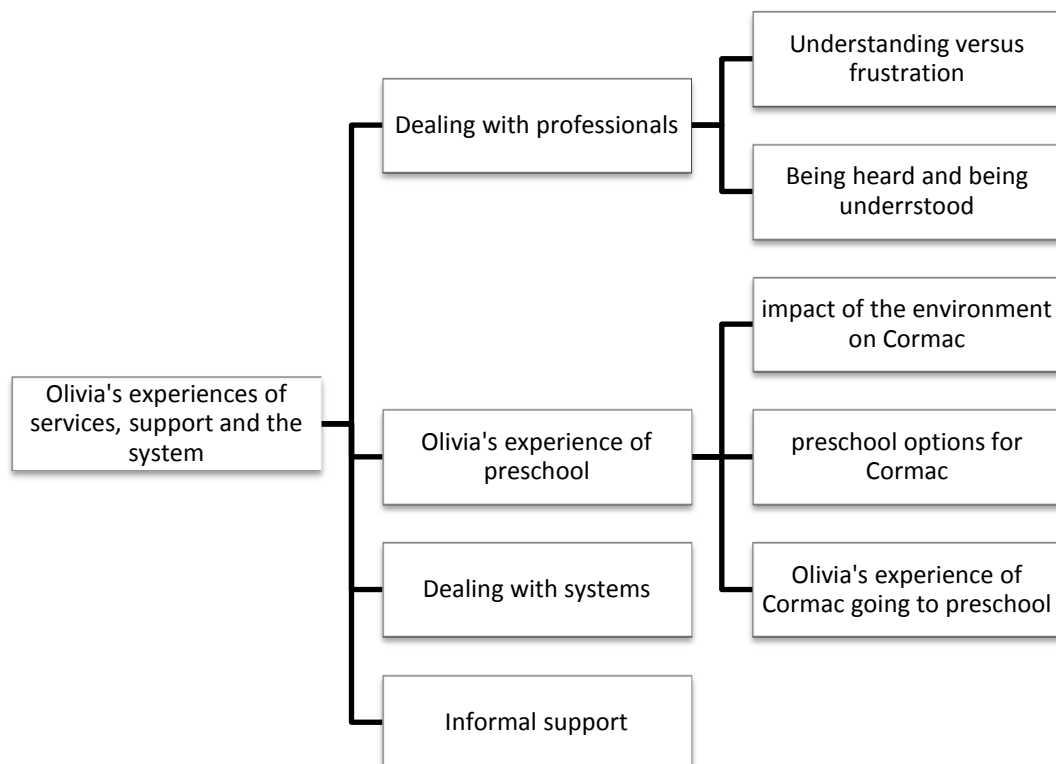


Figure 3.5 Overarching theme 'Olivia's experiences of services, support and the system'

In line with IPA's hermeneutic nature, I wrote out a summary of the narrative told by each participant in their interview and made reference to the themes that I identified within that text (please refer to Appendix 15 for a sample of an individual summary). In the case of Maria's interview transcript, for example, I charted the way in which some of the overarching themes related to each other and fit into the narrative account using a model described in figure 3.6 below:

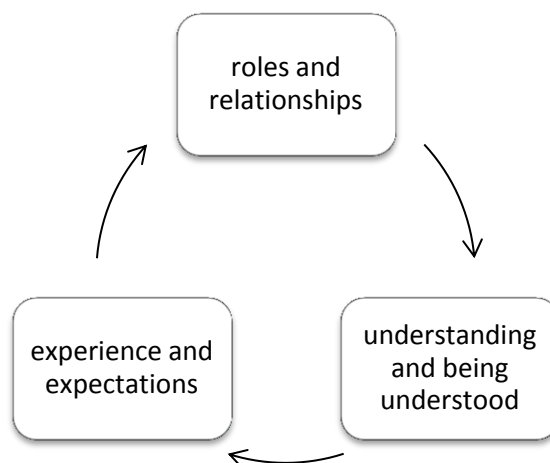


Figure 3.6 Relationship between overarching themes in Maria's transcript

This process might reflect the importance of relationships between Maria and school staff; good relationships lead to mutual respect and co-operation, thereby fostering understanding between all parties which impacts on expectations and experiences.

3.13.2.5 Step 5: Moving to the next case

In this step, the researcher moves on to the next participant's transcript and repeats this process. Smith et al. (2009) recommended bracketing away themes and ideas arising from previous cases because of IPA's idiographic nature. This may not be entirely possible as the researcher will be influenced by what has gone before. However, following the six steps in the analysis for each interview should enable the researcher to put the data in each individual transcript to the forefront and should help the researcher to deal with data from each transcript in its own right in line IPA's idiographic principles. In my analysis, each case

was fully explored before moving on to the next case. I made attempts to treat each case separately and tried not to be influenced by what went before.

3.13.2.6 Step 6: Looking for patterns across cases

This step involves looking at similarities and differences across cases. Smith et al. (2009) suggested organizing tables and figures spatially, across a large surface, to look for connections and patterns. Questions which explore how themes from different cases might add to, or impact on, each other are asked. Smith et al. (2009) recommended compiling a table of themes for the group of participants, wherein subordinate themes are nested within superordinate and overarching themes, with examples from each participant. To aid in the development of the overarching themes, I colour coded themes which appeared to cluster together. Please refer to Appendix 16 and to figure 3.7 below which provides an extract from Maeve and Maria's themes for an illustration of this process:

Being judged, being believed	
Maeve's feelings about sending her children to school Maeve's experience of school and educational staff Trying to make the right choices	Maeve's feelings about school and sending her children to school

Maria	
Themes and subthemes	Superordinate themes
Relationships with other people <ul style="list-style-type: none"> - Because I'm just their mum - Professional v parent / education v experience - Conflict with other people - Building relationships 	Maria's roles and relationships I'm young but I'm experienced
Maria's depiction of herself and her children <ul style="list-style-type: none"> - Young mother, student, advocate - About Paul and Donal 	
Trying to understand Paul Trying to understand the system <ul style="list-style-type: none"> - Maria's struggle to understand the system - Maria's feelings about conformity 	Understanding and being understood Why can't they just understand?
Trying to be understood <ul style="list-style-type: none"> - Maria trying to be heard - Paul trying to be heard 	
Maria's feelings about supports <ul style="list-style-type: none"> - Support for Paul in school - Support offered by Maria to the school - Changes in support for children with SEN 	Maria's experience and expectations of transition
Maria's experiences of preschool and school Maria's feelings about Paul starting school	

Figure 3.7 Extract from cross-case table of initial development of themes

In the above figure, the text which was highlighted in blue was clustered with themes from other participants' accounts and became the overarching theme "Preparing for school and feelings about the future". I found that making both graphic representations and tabular representations improved my ability see connections across themes. Themes that clustered meaningfully together, representing common patterns of experiences, feelings or perceptions, were noted. As I wrote, I found myself questioning and testing my thematic conceptualisations, and therefore the process of interpretation continued through the writing until I felt each theme represented the best conceptualisation of the data.

Smith et al.'s (2009) suggestion that a theme should occur in at least half of the cases was used as a guide to justify the development and selection of themes to cluster together into superordinate and overarching themes. Table

3.4 below illustrates the recurrence of subordinate, superordinate, and overarching themes for each participant as well as the number of participants who contributed to each theme, for example six out of six, or all participants contributed to the overarching theme “They’d need to *believe*, believe what we’re telling them”; In Maria’s case, for example, she contributed to 11 out of 14 of the overarching, superordinate, and subordinate themes.

Table 3.4 Recurrence of subordinate, superordinate and overarching themes

Themes	Maeve	Catherine	Tony	Olivia	Maria	Hannah	Number of participants per theme
They’d need to believe ...	Y	Y	Y	Y	Y	Y	6
Fighting for my child	Y	Y	Y	Y	Y	Y	6
Wanting to be heard ...	Y	Y	Y	Y	Y	Y	6
Experience of ASD ...	Y	Y	Y	Y	Y	Y	6
Is this how ...	Y	Y	Y	Y	N	Y	5
Initial reaction ...	Y	Y	Y	Y	N	N	4
Impact of timing ...	N	Y	Y	Y	N	Y	4
Meaning of ASD	Y	Y	Y	Y	Y	Y	6
Construction of ASD ...	Y	Y	Y	Y	Y	Y	6
Stigma ...	Y	Y	Y	Y	Y	Y	6
Preparing for school ...	Y	Y	Y	Y	Y	Y	6
Finding the right place	Y	Y	Y	Y	Y	Y	6
What I want for my child	Y	Y	N	Y	Y	Y	5
Feelings about future	Y	Y	Y	Y	Y	Y	6
Individual contribution to themes	13/14	14/14	13/14	14/14	11/14	13/14	

The table above shows that a minimum of 80% of participants contributed to the construction of each subordinate, superordinate, and overarching theme, thereby adding to the validity of the thematic

conceptualisation. Please refer to Appendix 17 for quotations from participants which evidence the development of themes across the cases.

Having identified themes which recurred across the cases, themes were mapped together in graphic form as outlined in figure 3.8. As can be seen, there was continual revision of clusters to make sure the overarching theme best represented the essence of the phenomena under review.

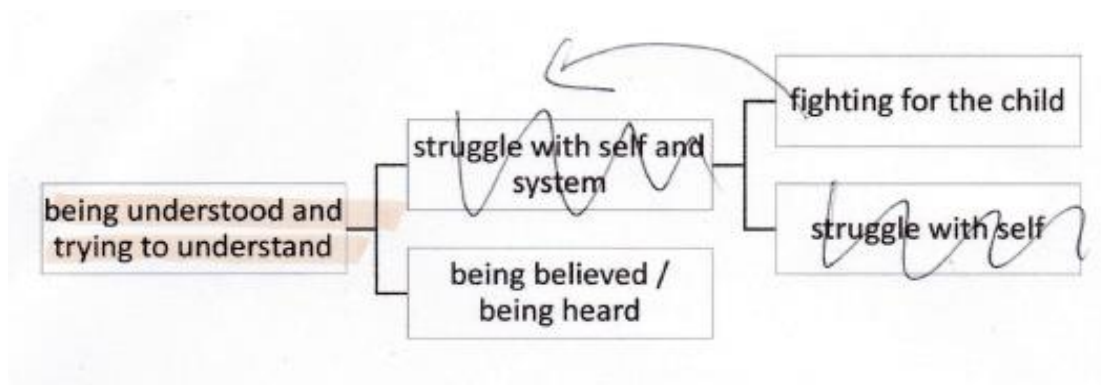


Figure 3.8 Clustering subordinate themes to develop overarching theme

Figure 3.8 shows the subsumption of the subordinate theme “Struggle with self” and the superordinate theme “Struggle with self and the system” into the superordinate theme “Fighting for my child”. It was felt that “Fighting for my child” captured the essence of this phenomenon for most participants as they spoke of struggling to secure resources and support and to have their child’s needs understood; in some cases, it reflected the inner conflict experienced in choosing the best course of action for the child. The initial overarching theme “Being understood and trying to understand” eventually became the overarching theme “I think they’d need to *believe*, believe what we’re telling them”, outlined in figure 3.9 below. The phrase was a direct quote from Maeve’s account which reflected the common concern among participants that they would be believed by other people.

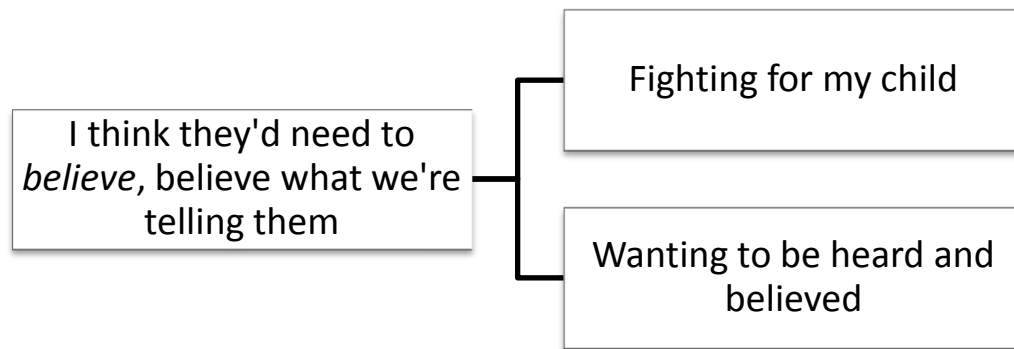


Figure 3.9 Overarching theme '*I think they'd need to believe, believe what we're telling them*'

During the process of writing up the findings, there was ongoing analysis and checking of themes against extracts of text to see whether the themes developed represented participants' experiences. Smith et al. (2009) suggested that the researcher should move away from the text as analysis progresses but I felt it was useful for me, as a novice, to check the validity of my interpretation against what participants said. In the next section, I will discuss the process of analysis and writing up the findings.

3.13.3 Analysis and writing up

Smith and Osborn (2003) maintained that writing up includes a further element of analysis as themes are translated into a narrative account. The table of themes is the basis of the account and extracts of what people said are used to illustrate the themes and support the interpretation. I found that as I wrote, I gained new insights into the data and began to move from a more descriptive to a more interpretative account.

I integrated the hermeneutic element into my analysis by conceptualising the hermeneutic circle at different levels of analysis. There are a number of ways in which the hermeneutic circle and the double hermeneutic process are evident in this study. Figure 3.10 below illustrates the interplay between the various factors in this process.

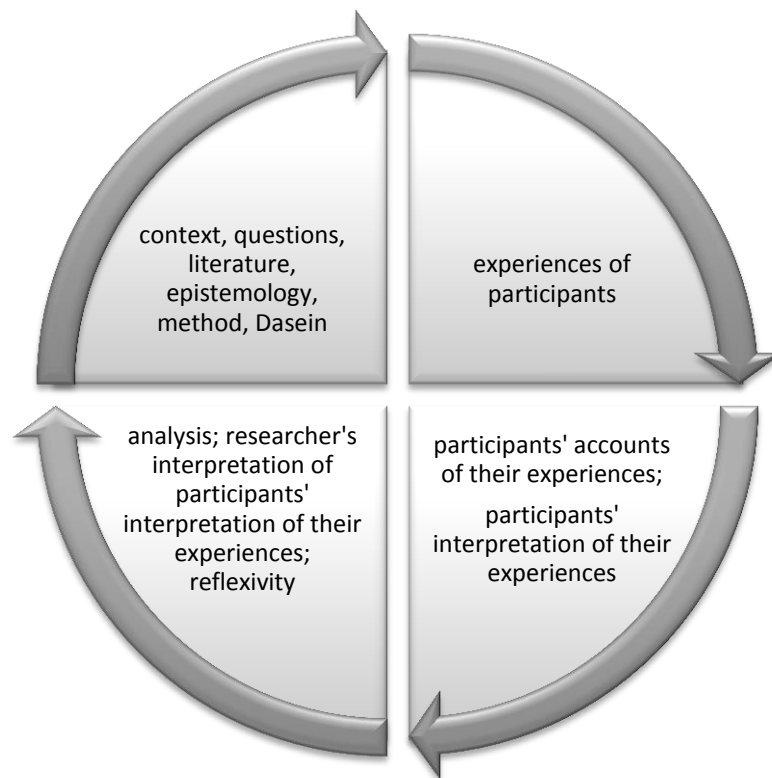


Figure 3.10 Aspects of the hermeneutic circle

The context includes the Dasein of the researcher and participants, the framework of the research questions, relevant research literature, and matters relating to epistemology and the method chosen. This research was conducted within a particular paradigmatic framework, critical realism, using a particular research method, IPA. The nature of the engagement with participants is relevant, as are factors such as the researcher's attempts to be reflexive, the participants' accounts of their experiences, their interpretation of their experiences, and the researcher's interpretation of their interpretations.

At each stage of the study and throughout the analysis of participants' accounts, I moved between different layers of interpretation. I read each text through as a narrative account and then investigated linguistic, conceptual and descriptive features of the text. Following this, I analysed and interpreted what individual participants' said about their experiences of particular phenomena, moving through different positions, from taking descriptive and empathic interpretations to taking a more interpretative stance. I then examined the hermeneutic circle within individual accounts, and then described the double hermeneutic of my interpretation. On completion of the individual exploration, I

analysed and interpreted experiences across the cases, and finally, I referred back to the research questions and the literature in Chapter Five to complete the circle.

It is recommended that the new researcher write separate analysis and discussion sections to link the analysis to the literature (Smith et al., 2009; Smith & Osborn, 2003). In keeping with this advice, I wrote up the analysis and discussion separately; the analysis and findings are presented in Chapter Four and the discussion is presented in Chapter Five.

3.14 Summary of Chapter Three

In Chapter Three, I discussed the method by which data was collected and analysed. This included discussion of the philosophical and epistemological frameworks underpinning the study. Phenomenology was the paradigm most suited to the exploration of the research questions, concerned as they were with people's experiences. A critical realist approach was appropriate to the manner in which these experiences were accessed and compared well with the method used, IPA. IPA typically involves the in-depth analysis of individual interviews with participants to find out about their perceptions and experiences. Phenomenology and hermeneutics are among the philosophical foundations of IPA. Husserl's focus on the person's experience of phenomena and Heidegger's notion of 'Dasein', the person's situatedness in their historical context, both complemented Bronfenbrenner's bioecological theory, which allows an exploration of the person's individual experience within their environment.

IPA suited the purposes of the study and allowed me to conduct an in-depth exploration of participants' experiences as well as a cross-case analysis to look at areas of commonality and divergence. I had briefly considered using another qualitative method, TA, but felt this method did not have the robust theoretical and philosophical basis that was necessary for the purposes of this study.

The manner in which I adopted a reflexive approach throughout the research and design was described in this chapter as were ethical considerations; an ethical approach was at the heart of my engagement with participants and their data. In this chapter, I outlined the design framework, including the timeframe and context in which the study took place; the

development of the interview schedule and the recruitment process. There were six participants in all, representing five children who were all starting school at the same time. The manner in which the interviews were undertaken was described as were the processes of transcription and analysis. Key commentators were consulted to support a robust application of the method and this is evidenced in the chapter. Questions around quality, validity and transferability of the findings were addressed and discussed and efforts made to adopt a rigorous approach to the research were described. I focussed on my role as researcher and demonstrated attempts to be reflexive throughout all the stages of the study. This gave me scope to examine the researcher's role and learn that one cannot 'bracket' assumptions to allow exploration of a particular phenomenon. Rather one can only be aware of one's assumptions and attempt to be explicit about the role these assumptions may have in the approach to the research. Having described the method, I will present the analysis and findings in the next chapter, Chapter Four.

4 ANALYSIS

4.1 Overview of Chapter Four

In this chapter, analysis from the interviews in this research study is developed and presented. The hermeneutic process is described in section 4.2 and a brief background to each participant and their child who was starting school is given in section 4.3. The interviews were analysed individually in line with IPA's idiographic nature and this detailed analysis can be seen in Appendices 13 to 17. On completion of the individual analyses, subordinate, superordinate, and overarching themes were identified across the cases. These are presented and discussed in section 4.4. Reference is made to areas of convergence and divergence between participants' accounts. Key extracts from participants' accounts are provided where they evidence the development of particular themes or where they illuminate the theme¹. Reference is made to reflexivity in section 4.5 and a summary of the chapter is presented in section 4.6.

4.2 Hermeneutic circle

As described in Chapter Three, the theoretical underpinnings of IPA are rooted in phenomenology and hermeneutics; phenomenology being the study of the individual's perceptions of phenomena (Smith et al., 2009) and the hermeneutic circle referring to the role of interpretation in the perception of phenomena (Smith & Eatough, 2006). In an IPA study, each participant interprets their own experience in their own particular way, reflecting Heidegger's concept of Dasein, or 'situatedness', which is the person's presence or existence in the context of their personal history. The double hermeneutic process in an IPA study involves the researcher being explicit about the impact of their own interpretation on the analysis of the participant's interpretation of a particular phenomenon. This analysis, therefore, presents an interpretation, *my* interpretation, of what each participant said about their experiences; the claim to represent their actual experiences is not made, merely the interpretation of their

¹ Page and line numbers are provided, for example: "Why should she?" (Tony, P.44, L.1540) so these can be cross-checked with the transcripts. Participants' names are included in brackets where appropriate.

experiences, or the interpretation of their interpretation of their experiences, is presented.

4.2.1 Exploration of the hermeneutic circle and the double hermeneutic

In the interpretation of participants' accounts I examined incidences of the hermeneutic circle. Participants evidenced their hermeneutic process in a number of ways, for example when they asked rhetorical questions: "How can nobody remember the basics?" (Maria, P.8, L.183) and "how can you judge when you are not in this house?" (Maeve, P.36, L.898); when they gave an account of their sense-making: "I thought how if she'll let her go even for a second, she'll be gone" (Catherine, P.23, L.772); when they reflected on how they felt about a particular situation or experience: "I felt like I was getting nowhere" (Olivia, P.5, L.114), and when they seemed to have conflicting opinions or feelings about an experience:

You're always kind of, am, kind of arguing – w- not arguing with yourself, like, but just "is it right?" (Hannah, P.12, L.368).

One hypothesis I held was that when people used rhetorical questions in their accounts, I was in some way accessing their thoughts on a subject directly, for example, when Maeve said "And I thought 'not all autistic children are like that'" (P.22, L.534) she was demonstrating her thought process and her reflection on her experience which was evidence of the hermeneutic process in action.

The double hermeneutic referred to my interpretation of what participants' said, for example, how I interpreted their sense-making within the context of their interview, how I interpreted it within the context of all the cases, and eventually, how I interpreted their experiences within the framework of the research questions and the research literature. When I used phrases such as "I felt", "I had the sense", and "this seemed to me", I was recording my sense-making, my impression forming, my interpreting, and evidencing the use of the double hermeneutic. By being reflexive, I attempted to be aware of my assumptions and role in interpretation. When the analysis was completed and

the overarching themes were developed, I referred back to the research questions and the literature to complete the hermeneutic circle.

4.3 The participants and their children with ASD

In this section, a brief background to the participants is given. Table 4.1 shows the participants and their children. As mentioned in Chapter Three, two of the children were to attend a special class attached to a mainstream school while the other three children were to attend mainstream school classes with some support. Three of the children had older siblings with ASD.

Table 4.1 Participants and their children

Parent(s)	Child
Maria	Paul
Maeve	David
Tony and Catherine	Chloe
Olivia	Cormac
Hannah	James

4.3.1 Maria and Paul

Paul was starting primary school for the second time. Maria, his mum, had enrolled him in school the previous September but had taken him out after a month as he was not settling in well. In fact, his toileting skills regressed when he started school initially and Maria felt this was due to anxiety on his part. Maria had an older child, Donal, who also had a diagnosis of ASD and she had been through a lot in relation to his experience in school. She'd had difficult encounters with school staff but she hoped these difficulties were behind her and she now felt that staff understood her better. She felt more able to negotiate the system and felt she understood better how it worked because she had learned from experience.

4.3.2 Maeve and David

Maeve spoke about her young son, David, who had attended a special preschool and a local mainstream preschool. She had found a place in a special

class attached to a mainstream school for him. This was a source of great relief to Maeve as she very concerned about David's lack of awareness around danger and his tendency to elope. David could climb out windows and had to be watched constantly. He had been knocked down by a car in the past. Maeve had an older boy with ASD who divided his time in school between a special class and a mainstream class. Maeve described life as being very difficult at home where the two boys "bounced off each other" and had to be watched constantly. Maeve told me that she and her husband went through "hell" but were trying to reclaim their lives by making time to exercise and become healthier of late.

4.3.3 Tony and Catherine and Chloe

Tony and Catherine were interviewed together. They spoke about their little girl, Chloe, who was due to attend a special class attached to a mainstream school. They talked about Chloe's strengths and also her issues. They were clearly very proud of Chloe and felt frustration when others didn't see her potential. They talked about waiting for, and receiving, Chloe's diagnosis and how little time her late diagnosis had left them to look for a suitable placement. Their main concerns were around her safety, as she had a tendency to elope, and her recent sensitivity to noise which impacted on their lives and restricted her freedom. They were due a new baby and Catherine, in particular, was very concerned that Chloe would be upset when the baby cried as this sound in particular made Chloe scream and lash out at her parents.

4.3.4 Olivia and Cormac

Olivia spoke about her little boy, Cormac, who was to attend his local mainstream school. At the time of the interview, he was attending his local preschool. Olivia had suspected that Cormac had ASD since he was very young and, though she had brought this up with professionals, his diagnosis was only finally confirmed when he was almost four. Olivia talked about the work she and her husband had put in to helping Cormac to overcome his difficulties, for example, they had spent two years teaching him to eat with a spoon. He was a bright child and Olivia was mainly concerned about Cormac fitting in and not

being segregated from others. She was conscious of the stigma that exists around ASD and worried about Cormac's future, in particular that he would have typical childhood experiences and would be included. Olivia talked about all the preparations she had to make to support the school who had not had a young child with ASD before. She was busy putting a pack together to give to school with information they would need to support Cormac.

4.3.5 *Hannah and James*

Hannah talked about her son, James, who had just started primary school. She had an older child with ASD who had received a diagnosis later on whilst in primary school. This experience had alerted Hannah to the possibility that James was presenting with similar features of ASD and she had him assessed also. To prepare James for school, Hannah had found a place for him in a special preschool for children with ASD and he had spent two years there. A year before James was to start school, Hannah had moved her middle child to the school James would be attending as she felt it was a more suitable school for James. That child was happy there which Hannah took to be a good indicator. Hannah was very concerned about James's future, about his anxiety, and about how he would fit in with other children. She spoke about stigma and worried that if people knew he had ASD, he would be excluded from play dates and parties. Hannah was happy with her choice of school but from her interview, it became apparent that she **had conflicting feelings** about the amount of support he would be getting there and she questioned herself about whether she had fought hard enough for support for him.

4.4 Principal analysis

In this section, the principal analysis from the study is presented. Figure 4.1 below illustrates the themes that I identified across the cases in the study. Overarching themes are represented on the left side, superordinate themes are represented in the middle of the figure, and subordinate themes are represented on the right side.

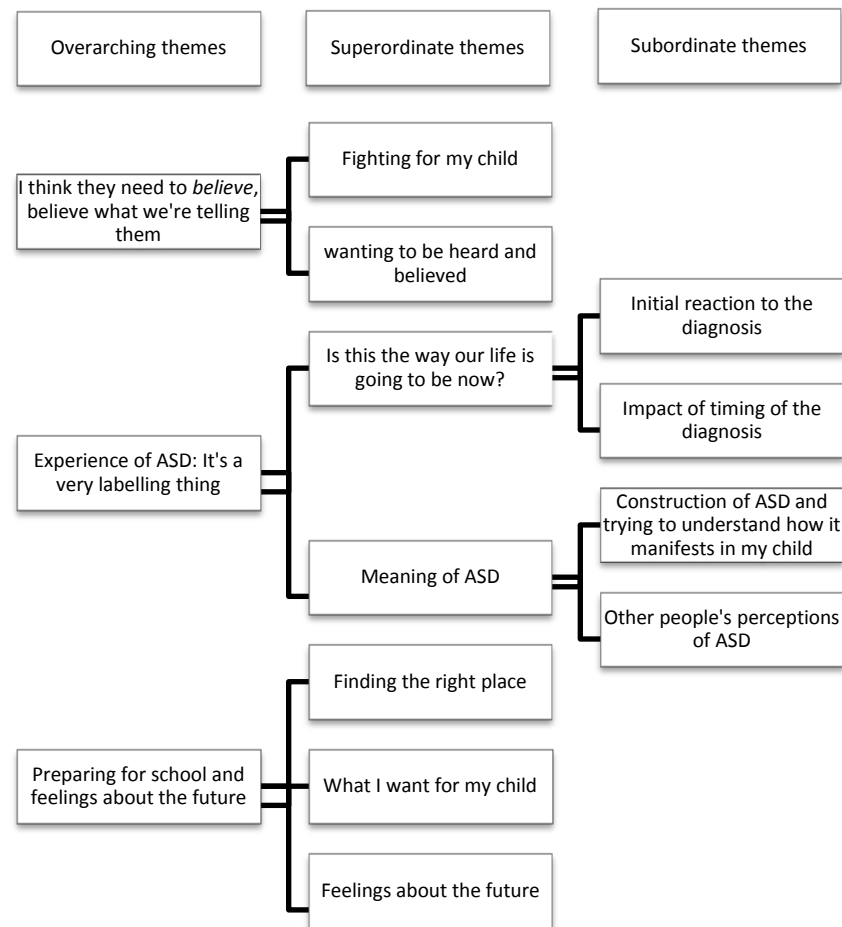


Figure 4.1 Overarching, superordinate and subordinate themes

In the following sections, I will provide an overview of the overarching themes and their superordinate and subordinate themes.

4.4.1 *'I think they need to believe, believe what we're telling them'*

This overarching theme comprised the superordinate themes ***'Fighting for my child'*** and ***'Wanting to be heard and believed'***. Participants talked about their struggle to secure supports and resources for their children and their desire to be understood and believed as outlined below.

4.4.1.1 *'Fighting for my child'*

This superordinate theme reflects the impression I got from participants of their sense of a struggle with professionals and with the educational system to find

the right educational placement for their children, to have their children understood, and to secure the support the children needed.

Catherine and Tony talked about their reactions to being told by professionals that Chloe was not developing as she should be:

And then when they (professionals) start telling you “Oh, she should be doing this; she should be doing that by now”, you’re just thinking “Why? Why should she?” (Tony, P.44, L.1539).

Yeah! You nearly get offended; you nearly get annoyed (Catherine, in response to Tony, P.44, L.1542).

Their tone when they spoke about this projected feelings of annoyance; defensiveness, and a protective attitude towards Chloe. In their interview they were concerned about how Chloe was perceived by others; that others didn’t see her potential and underestimated her ability. Tony’s use of the phrase “you’re just thinking” is evidence of the hermeneutic circle; Tony was stepping back and reflecting on what he was thinking and this gave an insight into his defensive, protective stance in relation to Chloe. When Catherine used the word “nearly” in the above extract, my impression was that this didn’t reflect her actual feelings of annoyance. I had the impression that she was articulating the annoyance and offence that she felt but was minimising it, perhaps out of politeness.

Hannah worried that James’s needs would be underestimated and that he would not get the support he needed. When he had attended a mainstream preschool initially, the staff had not noticed his tendency to be self-contained and isolated from peers and it was Hannah herself who had noticed that he went in everyday to the same spot in the room and played with trains on his own in a repetitive fashion. She was concerned that because he was quiet and well-behaved, people would think he did not need support. Hannah was very concerned about James’s anxiety which had led to regression in his toileting skills in the past. She **had conflicting feelings** and wondered had she done enough to secure a special needs assistant (SNA) for him:

I probably could have fought to get him an SNA maybe, but I think maybe in the long run, it's going to be .. all well; I hope it works out, do you know, it's a- it's really, it's on my head ... it's – it's still at the back of my mind I didn't - did I fight h- hard enough for him? (Hannah, P.12, L.357).

This uncertainty and self-questioning was evident in the above extract and other parts of Hannah's interview. In this extract, Hannah talked about what she thought would happen in the long run, however, she asked a rhetorical question "did if fight h- hard enough for him?" Her uncertainty is evident the words "probably" and "hope" but underneath this she was questioning the decisions she made. I felt Hannah's hesitancy in this extract, for example, "did I fight h- hard enough for him?" reflected the intensity of her uncertainty; this interpretation of Hannah's hesitancy in the context of her overall interview reflects what I perceived to be an ongoing conflict in her interview about her decisions in relation to James's education.

Maria talked about the manner in which she found school staff intimidating at times:

They can be quite intimidating (schools) and teachers from the school; there is that thing, you know, (they) have their degrees and they've been doing it for years, and ..even the way they would speak sometimes would come across quite intimidating, and .. that can be very hard to deal with when you're trying to .. essentially fight for your child (P.22, L.542).

Maria was very conscious of the school professionals' level of education and their experience and this seemed to impact significantly on her comfort levels when negotiating with them around her children's needs. She talked about what she perceived as hostility on the part of the school when she asked them why something went wrong for her sons in school:

I find the schools tend to nearly take offences to that (being asked why something is going wrong), almost like I'm trying to shift the blame onto them, instead of understanding: I'm not trying to get anyone into trouble

here – I’m trying to find out exactly what’s going wrong so we can fix the problem (P.22, L.529).

In the above extract Maria’s use of the phrase “I find” reflects the hermeneutic process as she reflects on the phenomenon of school staff taking offence at her questioning. At several points in Maria’s overall interview, she talked about being very young and referred to the relationship between parents and professionals, in which she seemed to feel disempowered by her youth and lack of experience. In the context of her overall interview, interpretation of the above extract suggests that Maria was trying to defend her position and explain why she questioned what happened in school. Maria was puzzled by the school’s tendency to misinterpret her motives. She talked about different occasions when she had to stand her ground to get the support her children needed. She recounted a particularly difficult experience when she had been called in to meet with the school’s board of management and their legal representative and had been pressurised to sign a document allowing them to physically restrain her older son in situations where he became aggressive. Maria did not sign the document but the consequences involved her spending the next **number of years** on standby for the school, ready to go in to collect her son whenever staff called her with a problem. Though she was calm in telling me about these events, I sensed that she had been deeply challenged by the conflict with school staff and this impacted on her dealings with them and her feelings about how her children would get on in school.

Though Maria found school staff intimidating, she had made efforts to overcome her feelings of trepidation and build mutual understanding with them because:

I think it’s very important for parents and the teachers to work together .. I know how important it is because there’s no way those teachers are going to know him as well as I do” (P.21, L. 520).

In this statement I got the impression that Maria was asserting and emphasising her authority and expertise as a parent and was in some way convincing herself that she had authority.

Olivia talked about having to adopt a different persona, going against her natural instincts, to fight her corner. There was a sense of preparing for battle and putting on armour in her adopting of a different persona to fight for what her child needed. In the following extract, Olivia steps back and interprets her experience in the context of preparing for conflict:

You're like fighting .. it's like fighting for your rights kind of thing (P.19, L.460); You have to push ... and get a bit of a thick skin as much as you mightn't be that person .. it's like a different persona you have to almost be .. to fight your corner (P.26, L.639).

Olivia made an interesting point in her interview about the difficulties parents had in negotiating the rules and the system at a time of heightened emotion:

That's what you're up against: the system which is a set of rules and you're dealing with parents, who are obviously from the emotional and just wanting the best for their children (P.32, L.782).

This point made me reflect on the fact that parents are often under stress when their children are starting school; from what participants said about their experiences, it seemed there was limited awareness or consideration on the part of professionals and the system in relation to their feelings at a difficult time.

4.4.1.2 'Wanting to be heard and believed'

This superordinate theme described how participants felt about being heard and being believed by family members and by professionals working with their children. I had the impression that participants had to deal with misunderstanding and misconceptions about ASD and a sense of frustration that people didn't believe what they said about their children and their own situations.

Catherine talked about how professionals perceived Chloe and how this differed from her understanding of her child:

They'd think that she doesn't understand what you mean but we know that she does, she's just being impatient and she's just being like any other kid would be ... other people looking at that ... would look at her and say "She doesn't understand that" but we know that she does (P.27, L.915).

There was a sense of frustration in Catherine's comment and in her repetition of the phrase "We know that she does". This comment highlights a concern that Catherine and Tony had about other people's understanding of Chloe's ability and her needs. They were frustrated that professionals who only saw Chloe for a short time in clinical settings, made negative judgements about her ability; they interpreted her difficulty following instructions as being due to difficulties with language comprehension, whereas Catherine and Tony's interpretation was that Chloe understood but didn't want to follow the instructions unless she was very motivated. In their interview, Catherine and Tony talked about their difficulty getting people to understand how extreme Chloe's tendency to elope was. Elopement refers to situations where a child runs off with no concern for safety. They felt they needed to constantly emphasise this to other people who didn't fully understand the extent of it; this was a source of major concern in their choice of school placement as they feared for Chloe's safety:

A lot of parents would say that about their kids: "Oh I leave him go for a second and he's ran off", but like it's not the same with her. She won't run to a road and stop. She'll run into the road. (Tony, P.24, L.790).

In the above extract, Tony implicitly said that Chloe is not like other children and that his experience as a parent is not like that of other parents; in his experience, other people did not believe how severe Chloe's elopement could be and almost dismissed Tony's concerns. This caused Tony and Catherine concern for Chloe's safety and they had to emphasise to people how much they needed to watch Chloe for her safety. This concern for Chloe's safety represents a contradiction between Tony and Catherine's desire that her

potential be seen by others and their concern that others would take her significant safety needs seriously.

Olivia talked about the manner in which educational staff seemed to listen to professionals more than they listened to parents:

When we spoke to the preschool .. they hear what you're saying but they don't take it on board as much as a professional and I always found from day one, if you could bring someone in then they tend to listen that bit more ... they listen to professionals more definitely (P.8, L.195).

In the above extract, Olivia talked about the difference between being heard and being listened to. In her opinion, educational staff heard what she said in an almost dismissive way, echoing her experience with professionals who had dismissed her concerns about Cormac in the past. They actively listened to professionals. She seemed resigned to this as is evidenced by the matter-of-fact nature of her statement, and she used it to her advantage, bringing professionals in to talk with educational staff when she could.

Maria was also worried that she would not be listened to as a parent. A source of considerable concern to her was that she would be heard at all by educational staff:

It's whether or not they'll hear me or not; that's what worries me (about school staff) (P.18, L.442).

She reflected on an assumption she had about school staff:

I do get the feeling if I, I don't know, if I had a child psychology degree or something, they would be begging me for advice but because I'm just their mum, that doesn't seem to count (P.14, L.335).

In this extract, Maria appears to feel that she would be seen differently and her position would be respected if she had a degree and it gave me the impression that Maria did not feel valued as a parent. Her use of the phrase "just their mum" seemed to position professionals at a superior level to parents

in her conceptualisation; I felt this contrasted with other parts of her interview where Maria was clear she had an important role in her child's education:

because as much as I'd like to have letters behind my name, and I don't have a degree in anything, but at the same time nobody knows him, and the issues that happen in school don't happen at all (at home) (P.5, L.108).

Though Maria valued the letters (degrees) that professionals had, she recognised that her children did not present with the same issues at home, and that she, as a parent, had her own expertise and knowledge and should be valued like professionals.

Like Olivia, Maria had also brought in professionals to support her in explaining the children's needs to school staff.

Maeve talked about an incident where staff in her older child, Peter's, school had told her they didn't think he had ASD and how this had affected her; she had been greatly upset about their questioning as is evident in the following extract:

It was awful. I was bawling crying (P.21, L.521).

This questioning seemed to undermine Maeve as a parent and as a person who experienced significant stress at home due to Peter's behavioural issues. I felt that when he was misunderstood, she was misunderstood and that this was hurtful for her. In the event, Peter had started to present with behaviour issues the following week. Maeve talked about being proud of him when he had started acting out in school because the subject of his diagnosis was suddenly dropped and she felt vindicated:

It just was marvellous and it was all forgotten about, do you know; the teacher couldn't handle him. I thought "brilliant"; I was delighted (P.23, L.559).

In this extract, Maeve's use of the phrase "I thought .." is evidence of her reflection and interpretation of the event and I had a sense of her triumphing against unfairness. When Peter's teacher wasn't able to manage his behaviour, Maeve was vindicated as a parent. Maeve's feelings about how unfair life could be was evidenced a number of times throughout her account, for example she wondered how people could judge her when they had no idea what her life was like and she gave a poignant account of a time when she had recently become upset about her life: "it's just so unfair that people get to enjoy their children" (P. 32, L.781). What Maeve had meant was that life was so hard with her children, she didn't get to enjoy them as other parents enjoyed their children. In this statement, Maeve was making an assumption that all parents enjoy their children. I had the impression that she felt her family and her experiences were outside the realm of typical family experiences so being believed about the challenges was very important to Maeve:

I think they'd need to *believe*, believe what we're telling them, not look at us as if that we're making this up on them. They make us feel as if we're bad parents, do you know, and we could be the worst parents in the world and we still wouldn't be going through this (P.33, L.819).

Having her older son's diagnosis called into question appeared to represent an indictment on her parenting. I felt there was an almost pleading tone to Maeve's statement: "They need to *believe*, believe what we're telling them". Maeve talked about "They" who didn't believe and who made her feel like she was the worst parent in the world as if "They" had power over her feelings and had the authority to judge her parenting. I had the impression that "They" referred to extended family members as well as professionals. A reading of her transcript shows that Maeve had put her own life on hold to raise the children and give them the support they needed. Her life seemed incredibly stressful and "very draining mentally ... because it's constant" (P.38, L.920). Maeve felt that she was judged unfairly and that even the "worst parents in the world" wouldn't go through the "hell" she described at home. Maeve also felt judged by her family who put some of the children's difficulties down to a lack of

discipline and compared her with a family member whose son had milder difficulties. She asked rhetorically:

How can you judge when you are not in this house? They don't see (P.36, L.898).

This question evidenced a hermeneutic aspect to Maeve's reflection on how other people perceived her and how this felt. She asked the question directly to the people who judged her and then stepped back to reflect: "They don't see". Maeve talked about people's perceptions of the government allowances and entitlements she received because of the boys' diagnoses:

If they think it's hand-outs we get in – whatever (P.38, L.942).

I felt there was hurt in Maeve's tone when she said this despite her seeming resignation.

Hannah also talked about being judged when family members would tell her there was nothing wrong with James:

Even in our own families, people say .. he is very high functioning ... that "There's not a thing wrong with him", you know; I'm sorry, I never asked for this ... It's not something I want and I suppose the fact that we don't tell people either that you'd think they'd understand, you know, that you know, we're just trying to understand him and get the best - the best out of him and the best for him, you know? But there's still a fair bit of stigma, even though it's a lot more common now, it's still ... and the- there's always that thing are they doing it for the benefits ...? (P.13, L.388).

Hannah's hurt was evident when she said "I'm sorry, I didn't ask for this (ASD)", in imaginary response. When Hannah used the phrase "I'm sorry" I felt she was being ironic. When she said "I didn't ask for this" I felt Hannah was being really honest and I got a sense of the rawness of her emotion. I had the impression that other people's disputing of the diagnosis compounded Hannah's grief. There was a sense of irony in this: Hannah worried all the time

about James but other people minimised his difficulties; she was the person who knew him best yet other people felt entitled to pronounce on his diagnosis. For Hannah, James's diagnosis represented a conflict between herself and family members who didn't believe her and it represented a conflict with others who didn't understand what ASD was. As is evident in the extract above, Hannah, like Maeve, had fears that other people would think she had her children diagnosed in order to receive government benefits. I noticed that Hannah was hesitant when talking about receiving benefits in the extract and felt this illustrated the strength of her discomfort around the idea of being judged in this way.

There was a sense of irony in the fact that the lives of participants could be so difficult and yet people did not often see or believe this. The metaphor of a swan came to my mind when considering this: The swan looks graceful and serene as it glides across the water but, unseen under the surface, its legs are paddling furiously. This metaphor attempts to capture my impression of participants trying to keep things normal for their children and families but behind this are feelings of anxiety, worry, grief, and fear about the future; feelings often unseen by others.

The next section provides an outline of the second overarching theme that I identified across the cases.

4.4.2 'Experience of ASD: It's a very labelling thing'

This overarching theme comprised the superordinate themes '***Is this the way our life is going to be now?***', which comprised the subordinate themes '***Initial reaction to the diagnosis***', and '***Impact of timing of the diagnosis***'. The superordinate theme '***Meaning of ASD***' was composed of the subordinate themes '***Construction of ASD and trying to understand how it manifests in my child***', and '***Other people's perceptions of ASD***'.

4.4.2.1 'Is this the way our life is going to be now?'

In this superordinate theme participants talked about the experience of being told their children's diagnoses and of the impact of the timing of the diagnosis on their experience of finding a school placement for the children.

4.4.2.1.1 'Initial reaction to the diagnosis'

Tony described his initial reaction to hearing that Chloe had ASD.

and that's the way we were thinking for a year and a half and then after that, for someone to say "yeah, there's a diagnosis of autism there", it's ... you can't mentally prepare yourself for that because you .. you won't see it in them, you won't, you'll never see anything wrong with them (P.43, L.1532).

Tony spoke about not being mentally prepared for Chloe's diagnosis because he had not seen Chloe as having anything wrong with her. He began by telling me how "we" were thinking when describing the experience and moved to using the pronoun "you" as he reflected on the fact that it was impossible to be mentally prepared. I felt that his use and repetition of "you won't" in the above extract was a way of generalising the experience and encouraging me to see things from his point of view. It also emphasised his resistance to the idea that Chloe had something wrong with her. As he explained:

When it's your child, all's you see, especially your first as well, all's you see is .. positive; you don't see anything bad about them at all so that whole year and a half while we were waiting (for the diagnostic assessment) ... we were just going: "Ah, there's nothing wrong, there's nothing wrong, she's perfect" (P.43, L.1517).

In this extract Tony moves from the reflective "all's you see" to the descriptive "while we were waiting". Tony didn't say the words shock or surprise but I felt that these feelings were implicit in what he said. His reaction to the diagnosis seemed to be linked to his personal construction of what ASD was, for example he had read that people with ASD were not affectionate. This difference between how Tony felt about Chloe (there's nothing wrong with her) and how professionals saw her (there's something wrong) seemed to be a

source of annoyance for Tony; **he questioned their opinion** that Chloe should be doing what everyone else was doing: “Why should she?” (P.44, L.1540).

Catherine: When they actually tell you ... it still comes as a bit of a blow ... it's like “Oh God”; it does come as a bit of a – a blow because you're like: “What am I going to do?” You kind of see things slipping away and little things ... you know, it's hard to explain because I think you think the worst whereas because we knew nothing about it, you know, and they just started talking about special classes and ... that comes as a bit of a sh- shock going “Oh my God” ... you start thinking all these horrible things that will happen which might never happen (P.43, L.1505).

Catherine talked about the shock of hearing that Chloe had ASD and the feeling of little things “slipping away” as if an uncontrollable force was taking hold and changing things forever. She used the word “blow” as if there was a physical sensation to this force. When the team giving the diagnosis started talking about special classes for Chloe, Catherine began to see a very different life for Chloe; she talked about fearing the worst and thinking of things that might never happen, as if her mind was suddenly racing ahead and anticipating terrible things in Chloe's future. There was a sense of helplessness and loss of control over life in the way Catherine described her feelings on hearing the diagnosis. She also talked about the difficulty that first-time parents may experience in seeing features of ASD in their child; she had concerns about Chloe's language development initially but hadn't realised that this meant she might have ASD. I had a sense of tension in what Catherine said; that she may have felt in some ways responsible that she hadn't seen signs of ASD in Chloe but that, as a first-time parent, she wouldn't have had the experience to do so. The hermeneutic circle is evidenced in Catherine's use of phrases such as “I think you think the worst” where she steps back and reflects on what she was thinking at the time.

Olivia spoke about how emotional it was to hear that Cormac had ASD and how this emotional state lasted for about a month:

and it was just very emotional; for a month any time I was thinking of stuff I felt like crying, do you know, because I was going ... just in the long run: “Is this the way our life is going to be now? That we’re kind of going to schools in <town> or, or do we have to look at moving?” Do you know, there’s a bigger picture in all of that then (P.11, L.255).

Like Catherine, the diagnosis seemed to signal major life changes and worry about the future, for example, Olivia worried initially that the family would have to move home to be nearer to special educational facilities. I sensed her uncertainty and perhaps some despair in the rhetorical question: “Is this the way our life is going to be now?” This question seemed to capture the feelings of other participants as they dealt with the shock and uncertainty of receiving the diagnosis. It also evidenced the hermeneutic circle as Olivia reflected on her feelings of disappointment and uncertainty around Cormac’s educational future. Like Maeve, Olivia spoke about positive features of ASD, for example, she felt that people with ASD speak the truth. Olivia spoke about Cormac’s communication difficulties which had been masked by his good language skills; she felt she had been fooled by this and hadn’t seen his issues with ASD. This contradicted in some way the fact that she’d had concerns about ASD since Cormac was very young and perhaps reflects a pattern of sometimes seeing the traits of ASD and, at other times, thinking that maybe the child doesn’t have ASD after all.

In contrast to the other participants, Maeve had been relieved to get the diagnosis:

Maeve: A lot of parents don’t like their children being labelled but we couldn’t wait (P.23, L.570).

Her experience of David’s issues was different to those of other parents; David’s issues seemed more obvious and more pronounced and impacted greatly on family life prior to the diagnosis. She had experience of her older boy having difficulty in mainstream and worried about sending David to mainstream school which she felt would be like sending him into a “house-fire” (P.20, L.230). Maeve felt that typically developing children could be cruel and believed that

children with special needs were generally kind to each other. Having a diagnosis of ASD meant that David was entitled to support and had access to a special class placement. In the context of her overall interview, I felt that David's access to special class was a concrete indication of his status as a child with special needs which contrasted with the view that his in-laws had of him as being a child who needed to be disciplined; this, for Maeve, was again a vindication of her parenting.

4.4.2.1.2 'Impact of timing of the diagnosis'

This subordinate theme reflected the timing of the children's diagnostic assessments. Catherine and Tony talked about their long wait for Chloe's assessment for ASD. Precious time had been wasted and they had missed out on specialised preschool places for her:

I think the fact that she didn't get diagnosed until she was four and a half years old hindered her for a lot of placements ... you've missed all the places, there's just not enough places (Catherine, P.40, L.1417).

I think that the struggle that we had in finding places for her was because ... the diagnosis of the assessment was coming close to the school time (Tony, P.39, L.1394).

In the above extract, Catherine moved from the personal pronoun "I think" to "you've missed" which I felt evidenced her move from a descriptive to an interpretative position. Tony attributed the "struggle" in finding school places to the length of time spent waiting for the diagnosis which he felt was "absolutely crazy" (P.42, L.1468) because it took so long for her to get a diagnosis and to get the help she needed. The diagnosis had come close to Chloe starting school and had left them with little time to find a suitable place which had caused much frustration and stress; as Catherine described it:

It was just that sinking feeling that she's not going to get anywhere and she's going to have to go in to somewhere where she's not supposed to be (P.45, L.1584).

I felt that Catherine's use of the phrase "sinking feeling" echoed her sense of things "slipping away" when she heard about Chloe's diagnosis. Here was another occasion when Catherine was surprised and shocked by events. She was worried that Chloe would now have to go somewhere she was not supposed to be; somewhere which would not be suitable. As it transpired, a place became available in a special class attached to a mainstream school: "We just lucked out" (Catherine, P.45, L.1588).

Catherine's expression gives an insight into what appears to be the tenuous position of parents and children with ASD who often do not know if a suitable school placement will become available. There is a juxtaposition between the luck they had in this instance and the length of time they spent waiting for Chloe to receive her diagnosis. Hannah and Olivia had a different experience to that of Tony and Catherine. Because their children had been diagnosed at a younger age, they were able to access some of the support and resources their children needed. Olivia talked about how information from professionals had increased her understanding of Cormac's needs and this is evidenced in the following extract:

We used be like "*What* is that?" we used just be *dumbfounded* at .. until then we started going to the OT (occupational therapist) when he was two and she was saying "oh, that's called motor planning" and when we heard what things were then we were going "that makes so much sense now" (P.39, L.958).

Olivia talked about her luck at having an early diagnosis for Cormac:

For us it's been a huge learning .. thing, like, and just because he is diagnosed so early we're lucky that we can work on all these things (P.42, L.1004).

His early diagnosis meant that she was able to understand his difficulties and was able to give him the help he needed.

Hannah spoke about her luck at having a neighbour who had valuable information about a special preschool for children with ASD:

When he was maybe about .. just turned three when we found out so luckily, my – I have a neighbour who has a son on the spectrum, she told me about the preschool in <town> and actually there was nothing else around so had I not known about that I would never have .. known to put him there and he got a year there and then we had to fight to get the second year and that gave me two years then to decide where to put him and at that stage we knew he was well able for .. mainstream and it was just a matter of finding the right school (P.1, L.8).

Hannah felt that having early intervention had been very important for James and without it, she wondered if he would have been ready to attend mainstream school:

Would he have been able for primary school?... I don't know. Maybe he would .. but .. I don't think so – not without all the intervention he's had (Hannah, P.27, L.818).

I had the impression, in the context of Hannah's overall interview, that despite having early intervention for James, she still had a lot of uncertainty and self-doubt about how James would get on in mainstream school and that she was in an uneasy position.

4.4.2.2 *'Meaning of ASD'*

This superordinate theme comprised the subordinate themes '**Construction of ASD and trying to understand how it manifests in my child**', and '**Other people's perceptions of ASD**'. Participants were not asked directly what it was like when they were told about their children's' diagnoses of ASD but the topic arose spontaneously and was linked to experiences of sending their children to school. Participants made references to their own constructions of ASD and their attempts to understand how it manifested in their children. I felt the construction of ASD was an important factor in the participant's understanding

of ASD, for example, Tony and Catherine thought children with ASD were not affectionate and so found it difficult to integrate this fact into their experience of Chloe who was very affectionate with them.

The concept of stigma was discussed by Olivia and Hannah whose children were going to attend a mainstream school. The perceptions of ASD that other people had and fears of their child being stigmatised were important factors in the participant's decisions about whether or not to disclose the child's diagnosis to others.

4.4.2.2.1 'Construction of ASD and trying to understand how it manifests in my child'

In this subordinate theme, participants spoke about their understanding of ASD and how the condition manifested in their children.

Maria felt that Paul was in many ways a typical five-year old who differed from his peers because his social understanding was less developed, for example, he forgot that he shouldn't hurt other children:

He forgets about not hurting others .. gets so locked into what he's doing he forgets to go (to the toilet) (P. 3, L.72).

Maria was able to understand the way in which he was different from others by seeing things from his point of view. In the extract above, she demonstrates her understanding of why Paul hit other children; because of his ASD, he didn't instinctively understand how other children would feel when he hurt them. Paul learned social rules at an intellectual rather than an instinctive level and would sometimes forget those rules. In looking at Maria's account, I was impressed by a tension between the ways in which Paul was like any other child and the ways in which he was different and that this was difficult for people to comprehend. Maria worried that school staff would forget that Paul had issues with social understanding and she found it frustrating that they would forget this key feature of children with ASD and this was evident in her rhetorical question: "How can nobody remember the basics?"(P.8, L.183). I had a sense of Maria's frustration when she asked this question and it seemed to embody many of the issues she had with school staff. Maria felt that young children

starting school were expected to conform to rigid school structures and systems to an extreme degree and feared that with such a “high level of conformity (in school) ... some children could get lost” (P.21, L.505). She felt this level of conformity was unfair on all young children as well as being unfair on her own children. In the above extract, I felt Maria was worried that her children could get lost in the system. She had sympathy for all young children starting school and felt that the preschool environment was a better one for them. Maria felt that all young children would need support starting school. I had the impression that in Maria’s mind, nobody was remembering “the basics” for all children and they were being expected to perform above their natural skills level, for example, Paul had been so anxious when he started school the first time that he lost his toileting skills and, at the time of the interview, was still wetting himself during the day. As mentioned in the previous section, Tony’s experience of Chloe as an affectionate, perfect little girl, contrasted greatly with his construction of ASD and with the construction of ASD presented in what he had read and what he had been told by others:

From what we read and stuff and what people have told us that some ... children with autism, that they don’t like physical contact, where she’s the opposite (P.20, L.649).

The information Tony had about ASD was of children who were aloof and didn’t like physical contact; this information did not reflect the kind of person Chloe was. I felt his construction of ASD made it difficult for him to see that Chloe had the condition. It seemed to me that, in Tony’s eyes, Chloe did not meet the criteria for ASD that he had researched. Catherine talked about the difficulty she experienced seeing that Chloe had issues:

I knew coming up on three that maybe she should be talking more ... I suppose you’re kind of thinking to yourself: “Should we have called someone in when she was two?” .. but you don’t know, you see, it’s your first child, you don’t know when they should be doing this, when they should be doing that (P.40, L.1417).

Catherine talked about questioning herself about whether she should have acted sooner to have Chloe assessed. Her uncertainty was compounded by the fact that Chloe was her first child. Catherine and Tony both described the difficulty first time parents had in seeing difficulties in their children. In the above extract, Catherine cites the lack of knowledge and experience about when children should be meeting developmental milestones. I had a sense that Catherine may have been experiencing regret that she hadn't known that Chloe needed more help when she was younger. Her move from "I knew" to "you don't see" echoed Tony's change from "I" to "you" in previous extracts. I felt Catherine may also have been encouraging me to see things from her point of view.

Maeve talked about the perceptions others had of ASD, for example, in her son's school, the staff had the perception that children with ASD flapped their hands and had poor eye contact. She felt that they didn't really understand what ASD was and that they didn't appreciate the difference between people on the ASD spectrum. From what Maeve said, I felt she herself was accepting of difference but felt that society in general did not accept difference. I sensed frustration when she talked about the pressure for everyone to be the same despite all their individual differences:

I just think there's so much pressure on society now that everyone has to be the same ... and they're not the same (P.36, L.881).

This pressure to be the same seemed to result in people who were different being judged and misunderstood; Maeve was judged as a parent and seen as deficient in some way, while her sons with ASD were seen as ill-disciplined and therefore, misunderstood.

Maeve's construction of ASD was in some ways a positive one, for example she wondered whether the world would be a better place if people were more autistic:

Sometimes I wonder should we all be a bit more autistic, do you know, and because they (people with ASD) just take people as they come, whereas, do you know, the mainstream; it's just such a worry and it's a horrible feeling dropping them there every day (P.35, L.867).

Maeve valued what she felt were common attributes of people with ASD such as being non-judgemental and accepting of difference. People who didn't have ASD appeared to Maeve to be intolerant of difference and were cruel to people who were different. Exposing her children to an environment where they could be excluded or teased worried her greatly. Maeve's reflection ("Sometimes I wonder") on the qualities of people with ASD and how they differed from typically developing people was evidence of her sense-making of the discrepancy between the qualities of typical people (who could be cruel) and people with ASD who were viewed negatively, and yet, who had very positive attributes. Maeve impressed me as being a person who stepped back from situations and events and made sense of them from a global perspective.

Olivia also talked about positive attributes of people with ASD, such as their truthfulness, compared to others without ASD:

It's like kids with ASD speak the truth it's the rest of us *don't* (laughs).
The rest of us are saying the niceties for the sake of it (P.56, L.1451).

In the above extract, she talks about the way in which typically developing people say things they don't mean as a matter of course. I had the impression that Olivia valued the truthfulness of people with ASD over the "niceties" of people who don't have ASD.

Olivia talked about how ASD manifested in Cormac:

He'd be full of chat ... but then you'd see, like social, he'd be looking away and like, speech-wise, he's always been grand ... but then his communication wouldn't be great which can fool people; and it fooled us for a long time as well (P.1, L.4).

Cormac was talkative and appeared like any typical child. However, his social communication was not typical. Olivia noted that his eye contact and reciprocal communication were issues. She made reference to having been "fooled" by Cormac's apparent skills as if he hadn't initially met her

understanding of what ASD was. Now she could see the subtle differences in his social communication although other people sometimes didn't.

Having an older child with ASD appeared to impact on how participants spoke about the diagnosis. Hannah, Maeve and Maria spoke less than Olivia, Catherine and Tony about the diagnostic process and receiving the diagnosis. Hannah felt James was very similar to his older brother and this had prompted Hannah to have him assessed. As he was so like his brother, who was academic and smart, she had a sense of how things would go for James in school and in the future. James met Hannah's expectations of what a child with ASD was like:

His speech is fairly monotone and he'd – speak for Ireland especially about his interests – they (other people) just think “Oh he's an old man” ... whereas .. like I – I see it – it affects him in school because the kids just run off and he's “but I wasn't finished talking”. Little things like that now and I know it's not .. do you know life-threatening or anything like that but still, you know, it's hurtful for him (P.14, L.419).

In this extract Hannah talks about features of ASD that James had such as monotone speech, talking at length about his own interests, and not understanding why other children ran away when he was talking. Other people saw these as merely character traits, but, for Hannah, they were a source of concern; she could see how these traits affected him and led to him being hurt. In relation to her older son, Hannah was able to say:

I often – not regret a few things with the older guy, we'll say, but you know, he's turned out fine, so I – I can't – can't be looking back all the time (P.19, L.578).

There was a sense of her older son being okay despite his late diagnosis. I had the impression that Hannah also appeared to have some regrets about his school experience, despite her saying “not regret”, and how difficult it had been for him because people didn't understand his tendency to ‘drift off’ or correct the teacher when they made a mistake in class. This was

evidenced in her comment “can’t be looking back all the time” as if she did look to the past too much. I felt I had the sense of Hannah trying to move forward with hope but having a constant internal struggle about doing the right things for her children. Elsewhere in her interview, Hannah showed that she also worried about the future too much and seemed caught in an uneasy present.

4.4.2.2.2 ‘Other people’s perceptions’ of ASD

Participants talked about stigma around ASD and other people’s perceptions of their children. Hannah mentioned stigma explicitly.

Because he’s so f- high functioning I really want him to fit in, you know, so we made the decision anyway, we told our neighbours, really neighbours and we’d have family; no one else really knows because I ... I don’t want the stigma of they – they won’t invite him to playdates now or he could be excluded (Hannah, P.13, L.374).

Hannah said she had told few people about James’s diagnosis and I had the impression that she felt that if people knew he had ASD they would look at him differently and he would be excluded from peer activities such as play dates. I felt that she was concerned here out James’s feelings. Her own feelings about stigma had influenced her choice of school placement. She had looked at a special class for children with ASD but ruled this out as an option because she did not want him to be stigmatised or seen as the child who went to the ‘unit’:

And you can hear parents talk about it – ‘oh that he’s one of the kids going to the unit’, they’d be saying ... If I have that – especially it being such a small town, you know – if my son goes to ‘the unit’, he’ll always be the kid that went – you know. It’s tough that way. So, I’m glad I had the choice that he .. was able for mainstream (Hannah, P.6, L.168).

In the above extract, Hannah reflects on her experience of other parents talking about the ‘unit’ and how this impacts on her; this was “tough”. I had the impression that Hannah was very aware of the stigma of ASD, in the way she

talked about other parents watching the children in the unit and hearing the talk about children in the unit. Hannah mentions the small town and I had the sense of her implicitly talking of 'small town mentality' where everyone watches everyone else and your history is always remembered. Hannah did not want stigma to follow James and perhaps, herself, throughout his life. She did not want him to be remembered as a child who was associated with the "unit". If James went to mainstream school, he would be less likely to suffer a stigma that would follow him in the future.

In the above extract, Hannah moves her position from "you can hear" to "If I have that" as if moving from the general expression of the phenomenon to its particular effect on her.

Olivia described the diagnosis as being a "*labelling* thing" and admitted that she herself had looked at children differently when she heard they had ASD:

When you get a diagnosis as well it's a very *labelling* thing and I've done it myself or "Oh, that child has autism" or and then ... you don't realise the levels *of* it and people are quick then to kind of .. not be dismissive or eh "Oh poor old Cormac" ... I don't want him to be that .. and we've deliberately not told *too* many people around here because the village is so small that, do you know, it's just talk, it's just idle talk that does the child no good or it's not their business either (P.54, L.1412).

This extract shows the hermeneutic process as Olivia moves from the position "when you get the diagnosis" to "I don't want him to be like that"; she is reflecting on how the general experience is for everyone to her particular wishes in relation to Cormac. Olivia didn't want Cormac to be pitied or singled out because of the diagnosis, and so, like Hannah, had told few people. Like Hannah, she didn't want the people in her small town gossiping about Cormac and discussing his issues because of the stigma associated with ASD.

While Hannah and Olivia spoke about wanting their children to fit in with others, Maeve felt there was too much societal pressure on people to be the same; her children were not the same as other people and people with ASD were different to each other. This echoed what Maria said about conformity; for

Maria all small children were different and their differences should be respected (Maria, P.21, L.505). Maeve feared for her children in mainstream situations because she had seen her older child, Peter, being excluded and felt typically developing children could be cruel. Even though Peter's peers were not including him, school staff seemed blind to his difficulties until he started acting out. His teacher felt that because he was "very good: he does his work" (P.21, L.525) he couldn't have ASD, as if a child with ASD couldn't be good and work well in school. Maeve felt that other people perceived ASD in terms of the "basics" by which she meant the stereotypical mannerisms, such as hand-flapping, associated with the condition:

I think people look for the .. the basics: poor eye contact, am, do you know, flapping hands and spinning, am, do you know being abrupt and .. do you know, they don't have awareness. Sometimes, they do; sometimes they don't. Do you know, they they're not going to tick all the boxes and I think that's what the schools think of autism is, do you know, if they don't tick all the boxes, then they're fine. It's just, do you know, maybe speech delays or something (P.22, L.544).

Maeve reflected on other people's construction of ASD in the above extract; she said people mentally ticked boxes in relation to ASD. This emphasis on searching for, and ticking off, symptoms of ASD meant that people had a reductive understanding of people with ASD and that, when they did not see the symptoms, they did not believe the child had ASD. This resonated with Maeve's wish to be believed. When she was called in to talk to the school principal, he told her about a child with ASD who had recently barged past him on the stairs, citing this rudeness or heedlessness as a symptom of the condition. Maeve disputed his narrow construction of ASD:

And I thought "Not all autistic children are like that". They're not, they're very different. That's why they've got a spectrum. Am, do you know, so I think "If you'd seen Peter at home, you'd put him at the far end of the spectrum" and say, do you know, there's been days when we've had 50 – 60 meltdowns with him (P.22, L.534).

Maeve spoke in the present tense “I think .. “ as if she was still mentally reliving this conversation with the principal. I got the impression that Maeve didn’t say this out loud to the principal at the time they met but thought it to herself, and was still thinking about it because she had been so upset by his misunderstanding and questioning of something so crucial as her son’s diagnosis. Her description of 50 to 60 meltdowns a day is very vivid and reflected her expression of life being “hell” at times. Because of the nature of her children’s difficulties, getting the label of ASD for her children was a relief for Maeve; they would have access to support and understanding without which life would be very difficult. In the context of Maeve’s interview, I had the impression that the label helped Maeve to understand that the children’s issues were not down to her parenting skills but were due to the disorder which was outside her control.

Catherine found people’s tendency to look at Chloe when she was in distress maddening:

And then she’ll scream and then you get people looking over at her and I get hyper and I get mad (P.3, L.102).

She moved from the position of “you get people looking over” to her own reaction: “I get hyper and I get mad”. I had the impression that this was due to embarrassment but also anger that people stared and didn’t understand what was happening and what the family were going through. Throughout many of the interviews, I noticed that participants sometimes moved from the general position when talking about interactions and situations as if moving from experiences anybody could have to their more particular feelings and thoughts on their experiences as in Catherine’s extract above. I had the impression that this helped them to make sense of, and to situate, their very particular and individual experiences in the context of what they felt people more generally and typically experienced. At other times, participants moved from the particular to the general position, for example, moving from “I know” to “you know” as if trying to involve me as a listener and encourage me to see things from their

perspective. I felt it was important to participants that I would understand their point of view and imagine myself in their position.

Tony talked about people misunderstanding Chloe's response to being asked to do things:

I think people have underestimated her a lot in the past ... they haven't seen her full potential there (ASD service) ... there's so many things that she can say and that she knows how to do and stuff but she just ... it's like she can't be bothered (P.18, L.580).

When Tony said "I think" he was evidencing the hermeneutic process as he reflected on the phenomenon of people underestimating Chloe. This was in contrast to his understanding of Chloe's ability. When Tony said this I found myself reflecting on this anomalous situation: why don't professionals incorporate the parent's knowledge and experience into the assessment; did the professionals know how Tony felt? And, if not, should the parent's understanding of their child be explored as part of the assessment process? Tony's frustration around this was evident when he asked the rhetorical question of Chloe in his interview:

You know all of this stuff but why .. you do this at home all the time, why are you not doing it now? (P.18, L.603).

Having discussed the second overarching theme, the third overarching theme is discussed in the next section.

4.4.3 'Preparing for school and feelings about the future'

The overarching theme '***Preparing for school and feelings about the future***' comprised the superordinate themes '***Finding the right place***', '***What I want for my child***', and '***Feelings about the future***'.

4.4.3.1 *'Finding the right place'*

This superordinate theme reflected the participants' attempts to find the right school placement for their children.

Olivia described the immediate pressure to look for a suitable school placement following Cormac's diagnosis; she didn't even have time to digest the news of his diagnosis:

We went from thinking he just had sensory processing disorder then to going: "Do we have to send him to a special school?" within a week ... we didn't even have time for it to sit to go "Right" (P.11, L.255).

Olivia's rhetorical question "do we have to send him to a special school?" evidenced her reflection and sense-making around this difficult time and seemed to sum up the uncertainty and worry about the future that accompanied the diagnosis. Olivia said she didn't have time to "sit" and digest this consequential information and this gave me the impression that this was a very unsettling time. I had the impression that she felt she didn't have time to grieve about the diagnosis, and of events taking over her life and family. This reminded me of Catherine and Tony, who spoke of having to look for a place so close to school starting. Olivia had looked at a special class for children with ASD as one of her options but this did not seem the right choice for Cormac. She worried that Cormac would copy some of the behaviours of children there and would pick up habits she'd rather he didn't learn. She also felt that children who went to special classes, or units, were in some ways segregated from other children and she didn't think this would be good for Cormac's development:

You want him to be able to go to the shop, do you know, ride his bike, do whatever, like. So at the end of the day, and he's right, you just want him to live a normal life so you want them just to be in with kids that they can just learn, do you know, not be kind of s- it's almost like a segregation thing (P.34, L.828).

Olivia wanted a normal life for Cormac and felt that if he had normal experiences, he would have a greater chance of having a more typical life. She talked about segregation in society as a comparison:

I find those ASD units are very good (yeah) but then you just have all the ASD kids in together, do you know what I mean? It's like society, do you know, let's put the social housing down there by themselves and have the private housing here. Nobody's kind of mixing in then like do you know? (P.32, L.787)

In this extract, I had the impression that Olivia saw the special classes as segregating and that by being in them, children were disadvantaged in some way. Olivia's comparison with segregated social housing implied that children in units or special classes were being left to one side by the school and, perhaps, by society. I felt she feared that by being in a special class, Cormac would be left to one side and left behind.

Hannah had put a lot of thought into finding the right place for James. Her older son had gone to a large school where Hannah felt he was just one among a number. She wanted something different for James. As mentioned above, she had moved her middle child into a small, local school a year prior to James starting and was happy with her choice and felt the staff there were proactive and helpful:

So I think this is perfect for him, you know, the small school, it's just what he needs. You can even see in everything – he's just so confident now since he's starting and he's talking with his friends (P.1, L.21).

Her use of the word "perfect" gave me the sense that she was really happy with the school; it was small and James was happy and this was what Hannah needed also. The school was evidently suiting James and his increased confidence and social interaction were tangible indicators of his progress. Hannah described the positive way in which his new school made the transition easier for young children:

She (the teacher) gave them labels in pre-preparation for bringing these (school books) back in September, you know: these will be on your books and it was really ah .. you know, kind of seamless transition. They really put ... a lot of effort into it (P.9, L.266).

Hannah appreciated the effort the school had made. She spoke about the kind of school she wanted for James:

I wanted somewhere that would kind of give him an arm around the shoulder without .. making him stand out from everyone else and that's what he's got; he's just got a little bit of extra guidance, like ... they wouldn't give him an SNA because he doesn't have any extra needs .. that's – eh – the term they use now (half laugh). Am, I kind of would have liked one, but at the same time I said I'm glad ... they think he's - doesn't need one (P.4, L.100).

In the above extract Hannah talks about her wish that James would be supported but not in a way that would make him stand out from other children. Her image of the arm around his shoulder is evocative. I had the impression that the perfect school would be one where he was protected and sheltered by a surrogate mother figure. Despite Hannah's wishes, James was not granted access to an SNA because the SENO felt he didn't have any extra needs. Her sense of conflict is manifest in her expression that she would have liked an SNA for James but was glad that the SENO and school staff felt he didn't need one. I felt that Hannah was not convinced that James didn't need an SNA and she referred a number of times throughout her interview to this issue. She talked about the process of getting more support for him which would have involved her writing a letter about James's difficulties:

It's very hard to do these things because you've got to write all his .. you know, am, needs and things; it's hard - writing it out and talking about it and trying to explain how bad it is. You feel like, you know, when you put it in writing about his – his needs that you .. I don't know, it's just very

hard going so maybe they should kind of do something like that – review (P.31, L.941).

The above quote is a good example of the hermeneutic process where Hannah is making sense of what it is like to be James. When she focused on James's difficulties, Hannah felt like she was stepping in his shoes and seeing things from his perspective; she found this insight upsetting: "You know you're kind of in his shoes and it's awful" (P.33, L.998). I felt that for Hannah, this emotional insight conflicted with the pragmatic task of trying to secure an inclusive education for James; she had to navigate between her understanding of how hard things were for him and the practical demands of life.

Hannah spoke about wanting to go in and talk to James's teacher about how he was getting on but she stopped herself. Though she wanted James to find his own feet, she felt she needed to give more input than parents of typically developing children:

I'm dying to go in and talk to the teacher but I'm saying just leave him settle, you know, just take a step back a while and if there's a problem, they come to you. And we just take every day – he comes out from the line but he, he's so happy. He seems so happy so ... just – take a step back now and don't be the parent that's always in. Even though you kind of – I suppose you have to be a bit more .. am, than the other parents, probably have to have a bit more input but. I'm trying to just let him find his own feet, you know. I really want him to (P.23, L.714).

In this extract, Hannah showed the urgency of her wish to go and talk to the teacher: "I'm dying to go in" but another voice was telling her to leave him settle in and take a step back. Hannah didn't want to be seen as a particular type of parent who is always going in to talk to the teacher. Hannah's statement "I really want him to" made me think that she was trying to convince herself that she really wanted to let him find his own feet because there was a big part of her that wanted to protect him. This extract gave me an insight into what it might be like for many parents who really want to find out what's happening in school but who feel they shouldn't go in or don't get the opportunity to do so. I felt this

was unfortunate for Hannah and for James as talking to the teacher would most likely be reassuring for Hannah and would have given the teacher a greater insight into James. It reflected an ongoing inner conflict and uncertainty which may not ever be resolved.

Olivia was also asked to write out a few lines on Cormac's needs. She had found meeting the SENO a frustrating experience as she felt that her concerns were dismissed somewhat:

When I came out from the SENO, I was just like .. a bull to a red rag (sic), like .. it was like I just found her very frustrating and a bit patronising because at the very end she said .. "He just seems like .." and I'm sure she meant it in .. the nicest way possible; she said, am "Oh he seems like any normal junior infant to me. He'll settle in in no time" (P.30, L.727).

The SENO's assertion, though undoubtedly well intentioned, was dismissive of Olivia's concerns and she was very frustrated by their meeting. Being told that Cormac seemed like any other child and would settle in quickly undermined the effort Olivia was putting in to preparing Cormac for school; I also felt the SENO's seeming complacency echoed the professionals who had felt Cormac was too young to be diagnosed in the past; they had also dismissed Olivia's concerns causing additional frustration.

Maeve had sent her older child to mainstream despite being offered a place in a special class and, in hindsight, felt she had been "stupid not to take it" (P.7, L.151) because he had struggled in mainstream. She was very concerned about finding the right school placement for David and felt a special class was the only option. Her concerns included David's lack of safety awareness and her fears that other children would laugh at him.

and I was very concerned .. he'd need to have a full time SNA in mainstream but I was still concerned but thankfully a space came up in a small national school out in the country and they had an autistic unit so it's taken all our fears away (P.1, L.25).

In contrast to Hannah and Olivia, Maeve was glad that David had a place in a unit. She felt her children had different needs and were different to other people and she wondered why children had to be integrated and included in mainstream which she felt was “great but it’s not for everybody” (P.10, L.249). She likened sending David into school to sending him into a house-fire, a very strong metaphor which reflected her worry and anxiety.

Maeve’s understanding of the difficulties faced by children who are different left her wondering why they had to be included:

Why can’t they (the government) have a school just for high functioning special needs children – it would make lives a lot easier for teachers, parents and children. Everyone would be happy (P.35, L.876).

In this extract, Maeve evidences the hermeneutic aspect, moving back from her particular position and taking a position relating more global concerns, where she reflects on educational provision for all children with SEN.

Maeve talked about her ideal option for her children’s education; being home-schooled. She regretted that she didn’t feel she would be able to manage both boys together: “I know that I would end up a quivering mess” (P.10, L.243). I sensed that Maeve may have blamed herself in some way for not being able to school the boys at home herself; this was what she considered the ideal but she would not have been able to manage them on her own.

How school staff were was important to Maeve and she felt that David’s new teacher was “wonderful .. she’s really nice, she’s understanding and she’s calm” (P.5, L.115). Though Maeve said the special class had taken all her fears away, she still had concerns about how safe David would be there:

That’s one of the main things the school needs to realise, just how severe that running is .. that he will climb out of anything. He’s climbed out of the sitting room window and run up the street naked many a time (P.29, L.721).

Given that David had previously been knocked down by a car, her worries were not unfounded.

Tony and Catherine talked about the experiences of trying to find the right place for Chloe who, like David, could elope without warning:

You're panicking over that going "How is she going to cope in the classroom, when she's running around them and you would just have everyone else affected by her ...disturbing the place?" ...it wouldn't be fair on her and I don't think she'd be getting what she needs (Catherine, P.11, L.368).

Before Chloe was diagnosed with ASD, Catherine and Tony had hoped to send her to a mainstream class despite worries about her language development. The first school to which they applied for a place said they could not meet her needs and this had caused some upset for Tony and Catherine who felt they had missed out on other options because of the long wait for Chloe's diagnosis; now they felt Chloe was being rejected because of her diagnosis. They were upset at the reaction of staff there who, in their opinion, "just saw her as a .. as a chore" (Tony, P.15, L.505). Catherine felt the staff in that school thought:

"Aw, she'd be too much trouble, she's just going to be a nuisance, so we don't want her" (P.15, L.507).

You don't want to send your child somewhere anyway where ... they just see her as a monster before they've even met her (Tony, P.10, L.327).

The terms that Catherine and Tony chose: chore, nuisance, and monster were very strong and reflected their upset and anger at the reaction of this school to their daughter's application. To Catherine and Tony this was a "bad experience" (Tony, P.15, L.477) which had made them think "is this what it's going to be like? Is this ... how people react?" (Tony, P.15, L.479). I felt they were trying to make sense of people's reaction to their daughter; once again, Chloe was being underestimated and misunderstood by people who were making assumptions about her on the basis of her diagnosis. I had the impression that Tony and Catherine felt they were misunderstood in the same

way that Chloe was misunderstood. Others didn't believe their accounts of their own daughter.

Catherine and Tony talked about the support they had received from their SENO in finding a place for Chloe:

from just basically finding the places ... she has all the contacts ... when we ..we both work so she'd be making phone calls for you, she'd be sending e-mails off for you and she'd basically do pretty much everything for you and then she'd come back to us with options (Tony, P.12, L.400).

I felt this extract showed some of the support that people need such as a key person who can advocate for them and who knows the right information, contacts and options. Catherine and Tony then applied to another mainstream school for a place for Chloe and had a very different experience. They were met with acceptance and they felt the principal was not judgmental. However, a meeting with Chloe's ASD team caused their plans to change again. The team felt Chloe would not be able to manage in a mainstream classroom and so Tony and Catherine had to look for a place in a special class. Tony described how their plans had changed:

I suppose we were thinking initially with mainstream is kind of "Throw her in the deep end .. she'll struggle, and over time, she'll catch up" but then we've kind of realised that that's .. not realistic (Tony, P.17, L.552).

In this extract, Tony reflects on the change in their attitudes towards Chloe's education and perhaps, their growing realisation that Chloe's needs were greater than they had anticipated. Catherine described the panic she felt when she met the ASD team and they told her that Chloe would be better off in a special class:

I had three (members of ASD team) around me and I thought "Oh God, this isn't good" and ... I went in and I said "Oh, oh God" (laughs) "this is not good news now" ... and then the panic came in – is she going to get a place? Because that was my .. just my main .. my main concern: it was

never “Oh, I don’t want to send her to special school”; it was never that ... trying to find somewhere for her ... that’s what it was, like, it was just that .. that .. sinking feeling (P.45, L.1570).

In the above extract, Catherine takes us through this difficult experience in a very vivid way. Her words evoked her rising panic about finding a suitable place for Chloe. Catherine wanted to make the point that it was not that she had something against special schools or special classes and she did not want people to have this opinion of her; she just wanted the right place. I was struck by her experience of having three members of the team around her and her interpretation of their presence; I wondered if she felt overwhelmed by their number and caught off guard as evidenced by her phrase “sinking feeling”, a phrase echoed in other parts of her interview.

With the SENO’s support, Catherine and Tony found a place for Chloe in a special class that had just been set up in a small country school where they felt she would be safe. Catherine described it as a “class with six kids, sounded like heaven to us, it’s a lovely country school ... it’s nice” (P.14, L.459). Like Maeve, how staff presented to Catherine was important:

I’ve met the principal. He’s lovely ... so friendly ... I came away just feeling really happy, saying “Please, please God, get her a place in here!” because even the couple of teachers that were going around, they were all so friendly ... you just got a really nice feeling out there which is .. what you want (P.14, L.466).

In this extract, Catherine talks about her gut feelings being important and that a nice feeling is what she wanted. In a similar manner, Maeve felt that when making the choice of place: a parent could “only go on instinct” (P.17, L.417).

Maria talked about relationships with staff as an important factor in her choice of schools for Paul. She had worked on her relationship with staff in the school where her older son was going and now felt they had an understanding of her and her children:

I get on very well now with (familiar teachers) where they .. just understand my method and they understand how you work with my kids (P.11, L. 263).

The above extract echoes Maria's sentiments about the expertise of parents. She knew what worked for her children and had methods which helped them. It was important that their teachers understood this and this understanding facilitated a good relationship. Maria felt that collaboration and communication between parents and teachers was important:

With children on the spectrum, it's again one of the basics ... structure is what works, so you need it to flow between home, professionals, school, if you need it – to flow. Obviously there will be slight differences because they're different areas .. but if everybody is working together, then the child has the security of knowing "everybody knows how I work" (P.23, L.575).

This extract illustrates Maria's reflection on best practice at a general level, which she then relates to what the individual child might feel.

Maria felt that a mainstream placement was the most suitable for Paul but she had concerns that he wouldn't get enough support because his needs "wouldn't necessarily be deemed as severe as others" (P.24, L.592). She was "unnerved" (P.18, L.436) that his ongoing issues with toileting would be an issue for school staff and she wasn't sure what stance they were going to take on this. Her primary concern was in relation to whether Paul would get the supports he needed and it was evident that Maria, despite feeling more confident about her relationship with staff, felt she had no control over this:

If has the supports he needs, he'll be fine ... it's whether or not he's going to get that (Maria, P.18, L.449).

4.4.3.2 'What I want for my child'

This superordinate theme encapsulated what participants wanted and hoped for their children in relation to their school placement and future education.

Hannah talked about her worries about James's social skills and her wish that James would fit in with others:

It's really his social skills that I'm kind of worried about, do you know that I really want him just to fit in kind of more. And sometimes, I think am I just conscious of it, that I can see – do you know, when he's running around and his hands are spinning? Am, or you know like ... maybe other parents don't notice, I don't know. Maybe we're just paranoid. But I really just want him to fit in another little bit, do you know ... he's so kind of .. like, he kind of *is* like an old man sometimes, you know that? And I'd be just like "Please God, let him just get through school, go to college" and you know, not be worried. You know (laughs) I really hope he will (P.21, L.622).

In the above extract, the hermeneutic process is seen in her reflection on her concerns and her question as to whether she was the only one who was conscious of it; she wondered if other parents noticed his idiosyncratic behaviours such as hand flapping and spinning in circles. Hannah hoped he would get through school and get to college and that his anxiety wouldn't affect him. I also felt that she hoped she wouldn't always be so worried about him. There seemed to be an urgent tone in Hannah's entreaty: "Please God ..."

Like Hannah, Olivia wanted Cormac to fit in and be as typical as he could be:

I suppose a big thing for me is that .. yeah, he'll learn, but that he'll *cope* around people and make friends. And, am, I suppose just be able to be a typical little boy as much as he can be. Not to sound whatever .. and that that actually to *be* that is actually a lot .. but not to be *too* different (P.53, L.1397).

Olivia wanted Cormac to have friends and not be too different from other children. I felt this was linked to her worries about stigma; that his being perceived as different by others would lead to segregation and isolation. When Olivia said she didn't want to "sound whatever" I took this to mean she didn't

want to sound like she was stigmatising children who were different. I also got the sense from the above extract that she knew Cormac would be different in some ways, but she hoped he wouldn't be "too different". In this extract Olivia reflects the complexity of stigma; she is aware of stigma and admits to stigmatising people in some ways but doesn't want to be seen as stigmatising; furthermore, she doesn't want Cormac to be stigmatised in the future.

Catherine wanted Chloe to be happy in school and worried that her noise sensitivity would cause her such upset that she wouldn't cope and that her experiences in school would be negatively affected:

I just don't want her coming home every day upset. When she's being upset, it's ruining it for her and then you feel like aw-, it's ... such a shame, you know because she – she's so capable of a lot of things ... they kind of probably think then "Oh sure she can't do that" (P.32, L.1075).

The concern about noise sensitivity arose a number of times throughout Catherine's interview; she didn't want Chloe's enjoyment of things to be ruined by her noise sensitivity or by the restrictions that were put on her because of her tendency to elope. She worried that if Chloe was upset by noise in school, staff there wouldn't see her potential. I had the impression that Catherine was worried that Chloe would be 'written off' in some way; she had been rejected by one school already and the professionals who assessed her hadn't seen her potential.

Maeve also wanted her children to be happy in school. She was not concerned about how they did academically as long as they were safe and were not teased by others:

I don't care if they come out with their leaving cert. (state final examinations) or anything once they are happy (P.12, L.280).

Maria thought that all young children were different to each other and had their own "eccentricities" (P.19, L.465):

At that age, kids are all pretty much the same ... and they all have their little eccentricities and the things that they like and the things that they'll get locked into .. so the things that could be put in place like giving prior notice to what's going to happen and things like that – I think that would work for all kids across the board, to have them all understand (P.19, L.465).

Maria felt that they would all benefit from the use of strategies to support their understanding; the kind of strategies which were typically recommended for children with ASD in school such as being pre-warned about change and having things properly explained. She felt the difference and individuality of young children were not acknowledged in primary school and that this could lead to some children getting “lost” (P.21, L.505). Maria's link between children conforming and getting lost gave me the impression that she felt children lost their identity to some extent when they had to conform. In her interview, Maria had interpreted her older son's aggression in school as him feeling “a bit lost ... it worked for him (when he was aggressive)” (P. 11, L.273). Maria seemed to feel that conforming hadn't worked for her son and may not work for all children.

4.4.3.3 'Feelings about the future'

This superordinate theme reflected participants' hopes and fears for the future, both in terms of their children's future and also for their own futures. Participants spoke of their concerns about the children's experiences in school and also their thoughts about how life was going to turn out for themselves as time went on. Concerns about the children's future education and their own futures seemed inextricably linked; it seemed that their children's adjustment to school would be an indicator of their children's progress in the future. If the children succeeded in school, the future might be less worrisome and more hopeful for parents.

Olivia talked about having a lot to cope with in the first two years after Cormac's diagnosis; with the passage of time, she realised that issues would arise from time to time for Cormac but she could cope:

I think as time goes on anyway you realise .. I think the first few years it's all so much. As time goes on, do you know, it's just like, do you know we can deal with it ... and like that, things arise just day to day anyway ... it's like anything, if you think of the bigger picture, it's like "Oh Jesus .."
(laughs): break it down, it's all right (P.56, L.1471).

Olivia found looking at the bigger picture (the future) difficult as expressed in her exclamation "Oh Jesus!" and found it easier to take things day by day. Here, Olivia steps back and reflects on her difficulty looking at the bigger picture and that the only way to cope was to take things day by day. I had the impression that the bigger picture represented Olivia's future and her family's future and that this was something frightening for Olivia to contemplate. Her future was bound up in Cormac's future and I had the sense that she foresaw worry as being a constant feature in her future life:

The school will be grand – I'm not worried about that; it's just more the behaviours and .. basically will he make friends? that's what you're actually worried .. for all the other things you're fighting for like at the end of the day you don't want him to be ostracised or, do you know not making friends and feeling .. do you know being bullied or bullying (P.52, L.1363).

Like Hannah and Maeve, Olivia did not want her child to be ostracised, or friendless, or bullied. She was also aware, because of Cormac's issues with social understanding, that he could become a bully, for example, by taking over games that he played with other children.

Tony spoke with hope about Chloe's noise sensitivity and felt that she would find a way to cope with it in the future:

She's not going to be ... like that (noise sensitive) for her entire life.
She's obviously going to find a way to cope with it (P.5, L.169).

In the context of his interview, Tony seemed to have a confidence in her that she would adapt and learn and grow over time. I had the impression that he

may have been trying to reassure Catherine who was distressed about Chloe's noise sensitivity. Like Catherine, however, he was concerned about Chloe's quality of life:

We can't wait for that (noise sensitivity) to – to pass, and God knows how long that's going to be because it's ... one of those things where you feel like things are being ruined for her" (P.25, L.843).

Catherine was not hopeful about Chloe's sensitivity to noise:

It's the constant worry now on my mind constant, constant worry. I'm panicking. How I'm going to cope with ... I don't know how she's going to do and it's like we don't know is there anything we can do to help it. You know, and to .. make it better because I was – I think I'm going to end up in <mental hospital> (laughs) with the stress. I don't know what I'm going to do because there's no way I'm going to be able to manage a ... screaming new baby and her trying to attack me ... she will attack you with her nails and she'll get mad and she'll scratch you ... I don't know how I'm going to cope with it I really don't (P.33, L.1094).

For Catherine, it had come out of nowhere:

All of a sudden in the last couple of months – anything can set her off ... we're getting to the point where we nearly can't take her anywhere" (P.3, L.96).

I felt this sudden development had taken her by surprise and perhaps foreshadowed a future of unseen difficulties. Towards the end of their interview, Catherine expressed very tangible fears about how Chloe would react to the new baby. She talked about feeling panic, stress and constant worry about how she would cope. Her extract illustrates this sense of panic, for example, in her repetition of the word "constant" and repetition of the phrase "I don't know ...". Catherine's feelings, so vividly expressed, evidenced her sense-making around

Chloe's issues and how they impacted on her own life; Catherine's life was now stressful and filled with constant worry about the future.

Hannah talked about her tendency to look to the future and this seemed to be linked in part to her fear that she would be responsible if James didn't reach his potential:

I always look to the future; just always hope that ... God I hope that (I) didn't hold him back now, you know or that. I suppose, really, relationship – relationships (P.21, L.645).

Throughout her interview, Hannah made references to uncertainty about decisions she made for James. She questioned herself a number of times showing evidence of the hermeneutic process. There seemed to be a tension between her head ("I know") and her heart ("I hope") as illustrated in the following extract:

I know they'll do fine, well I hope they will. Sometimes you hear of these kids who just fall through the net and you know they have all the ability but not .. you know, there's that side of it too, you know. So you've kind of the constant worry that .. just get through life. And sometimes you feel like are you being an overbearing mother that – do you know – force them the whole time or should you take a step back. (P.22, L.666).

The above extract reveals Hannah's expression of constant worry which mirrors Catherine's. She questioned her own parenting, wondering whether she was an overbearing mother, putting her children outside their comfort zones, into situations where they were anxious, or whether she should let them follow their own natural developmental path. Again, there was a sense of Hannah's uncertainty about making choices or knowing the right thing to do. Her worry about her children's future was evident in the following extract:

It's just an awful worry that they won't .. you know maintain friendships and build on them when you get that bit older. You know, you'd hate for

them to be a loner or just .. am, you know especially when they're into technology, they just get *lost* in it (P.22, L.654).

This extract gave me the sense that Hannah's worry would continue into the future and that she feared her children would become adults who stayed away from other people and were consumed by technology. Maeve also talked about making the right choice. In the past, she felt she had made the wrong choice of educational placement with her older boy, Peter:

Now we've got choices with David, and hopefully we're making the right ones this time (P.17, L.402).

Maeve was very pleased with the option of special class for David: "I think this is going to be the making of David" (P.11, L.269). This statement represented a hopeful outlook; the right placement meant that David was more likely to be safe and happy.

Maeve was concerned with immediate issues relating to her life, which seemed very difficult. She described the situation thus: "We don't (manage), no, but ... slowly, do you know, we're trying to adapt" (P.4, L.85). There was some hope for her future in that Maeve and her husband were trying to get their lives back on track: "So we do try, now we've joined the gym, so I'm trying" (P.39, L.947). I had the impression that Maeve's repeated use of the word "trying" indicated how difficult and effortful life was at times for her and her husband. In these extracts, Maeve reflects on her life and her attempts to get through very difficult times. Towards the end of her interview, Maeve had a hopeful tone and there was a sense of life returning to manageable proportion, in some part due to the children being in the right educational setting.

Maria felt she had developed as a person and was more confident that she could go into the school and get the staff there to listen to her:

I was very young then and I didn't understand how everything worked. Now I understand it a bit more so I have that bit more confidence to go in and go 'Listen ...' (P.13, L.307).

However, she had reservations about how much the school would take her advice:

As much as schools want support and they want people coming in showing them how to handle situations, they kind of don't like being told what to do, so you can give them all the information in the world, it's up to them whether they use it (P.23, L.568).

I felt the above extract was evidence of Maria's sense-making in relation to the powerlessness she felt in her relationship with the school and the educational system; at the end of the day schools had the final say about what information they took on board or what supports they put in place, despite the knowledge and experience of parents. Reflexivity in the analysis of the findings will be discussed in the next section.

4.5 Reflexivity

In Chapter Three, I outlined ways in which I attempted to implement a reflexive approach in this research by being explicit about reflexivity at each stage in the research process, from the thematizing stage to the interpretative and writing up phases. A reflexive account is given at the end of each individual analysis wherein I discussed my feelings and perceptions in relation to each interview (Appendix 12).

I found the analysis of individual cases and the cross-case analysis quite challenging initially. It took me some time to be at ease with the interpretative and hermeneutic aspects of IPA; to move beyond a descriptive analysis to a more interpretative stance. Following discussion with my supervisors and much reflection, I realised that there is freedom in IPA to be explicit about one's role as interpreter; one can be explicit about the extent to which the interpretation is one's own construction rather than a claim to 'truth'.

By being explicit about my role as interpreter, I felt I could attempt to expiate some of the 'authority' and 'power' of the researcher in relation to the construction of meaning. As mentioned previously, I wrote an imaginary letter to participants to explain that I was interpreting their words and accounts and to take ownership of my interpretation (please refer to Appendix 4). Having written

the letter, I became more comfortable in moving beyond a descriptive analysis of themes to a more interpretative and hermeneutic examination of participants' sense making around their experiences.

In the analysis of what participants said about different experiences, there were times when I found myself reacting to what they said, for example, when Catherine said that professionals didn't think Chloe understood certain things which Catherine was confident Chloe did indeed understand, I found myself doubting Chloe's understanding. When I thought about this further, I found myself taking what Catherine said at face value and interpreted what she said in an empathic way. Listening to participants' accounts and analysing what they said made me more likely to believe what they said and take what they said at face value. This made a more interpretative analysis more challenging for a time but after reflecting on this and on the nature of the method, having written my imaginary letter, and through practice, I became more confident taking an interpretative stance.

As a member of an MDT, I was interested to hear about participants' experiences of MDT support services; I was conscious of hoping participants would say positive things about therapeutic staff. I made a mental note of this and of my reactions to what they said and attempted to put these to one side, to set aside my assumptions, and interpret what people said in the context of their personal experiences, for example, when Catherine spoke about meeting the MDT and her feelings, I was embarrassed that the meeting had that been like that for her. I began to think about times I had given feedback to parents, or broken bad news and questioned myself about whether I had caused those feelings for those parents. I then tried to remember that this was Catherine's story and as researcher, I needed to step back and interpret her story as neutrally as possible; I needed to acknowledge my own assumptions; experiences, and feelings but keep them separate from my interpretation of participants' experiences.

4.6 Summary of Chapter Four

In Chapter Four I described the participants, of whom there were six in all, and their five children. I discussed the hermeneutic circle and the double hermeneutic, two features of analysis in IPA, whereby the researcher

documents and explores their sense-making around the meaning participants make of their experiences. This process was evidenced throughout the chapter. I discussed issues relating to reflexivity in the analysis of the participants' accounts. Findings from the study were discussed in detail, including an analysis of subordinate, superordinate and overarching themes across the cases of the six participants. These were evidenced and illustrated using extracts from the interviews.

I identified three superordinate themes which I felt encompassed the experiences and perceptions of all the participants, namely, '*I think they need to believe, believe what we're telling them*'; '*Experience of ASD: It's a very labelling thing*', and '*Preparing for school and feelings about the future*'. These were composed of four subordinate and seven superordinate themes which clustered together as illustrated in Table 4.2 below.

Table 4.2 Subordinate, superordinate and overarching themes identified across the cases

Subordinate and superordinate themes	Overarching themes
Fighting for my child	I think they'd need to <i>believe</i> , believe what we're telling them
Wanting to be heard and believed	
Is this the way our life is going to be now?	Experience of ASD: It's a very <i>labelling thing</i>
- Initial reaction to the diagnosis	
- Impact of timing of the diagnosis	
Meaning of ASD	
- Construction of ASD and trying to understand how it manifests in my child	
- Other people's perceptions of ASD	
Finding the right place	Preparing for school and feelings about the future
What I want for my child	
Feelings about the future	

These themes describe the feelings and experiences that participants had in their dealings with professionals and others in relation to their children's education. Areas of commonality and divergence were identified within themes, for example, some participants struggled with their child's diagnosis of ASD,

while others were happy to have a diagnosis which would enable them to access appropriate services.

In general, there was a sense from participants of their struggle to be heard, to have their own perspectives understood and to have their children's characteristics and needs understood. Participants talked about the impact of the diagnosis on themselves and their families, and the impact of the manifestation of their children's ASD on their lives. They talked of their struggle to understand the condition and how it presented in the children. Finally, they spoke of preparing their children for school and their hopes and feelings for the future. A multitude of feelings were described including hope and worry. In this chapter, the findings present my account of the perceptions and experiences of these six participants in relation to their children starting school. I have outlined my attempts to be reflexive and to acknowledge my role in interpretation of the data.

In Chapter Five, the findings will be discussed in relation to the research questions and in the context of the existing research literature. A critique of the study, its method, and findings is presented. Outcomes will be discussed with reference to the study's relevance to the roles of the EP and other professionals working with children with ASD and their families.

5 DISCUSSION

5.1 Overview of Chapter Five

In this chapter, the present research study is discussed and critiqued. The findings from the study are considered in the context of the research questions and the research literature in section 5.2. A critical evaluation of the method is provided in section 5.3, which includes an evaluation of the theoretical underpinnings of the present study. In section 5.4, further research questions are identified and the relevance of the findings to the work of an educational psychologist (EP) is discussed. The manner in which the research findings make a distinct and significant contribution to knowledge is outlined. The outcomes of the study and implications that the findings have for the work of EPs and other professionals are discussed. Section 5.5 provides a summary of the chapter.

5.2 Relating research questions to findings

This study set out to explore the experiences of parents whose children with ASD were starting primary school. A gap was identified in knowledge about this topic. Furthermore, a gap was identified in the literature around what is known about the experiences of parents of typically developing children who are starting school, both in Ireland and internationally.

Findings in this study are encapsulated in the overarching, superordinate, and subordinate themes that were identified in participants' individual interview transcripts and across the cases as detailed in Chapter Four. The cross-case findings and their relationship to the research questions and the research literature is discussed in the following sections. Three overarching themes were identified which comprised a number of superordinate and subordinate themes. The overarching themes identified were as follows: ***'Experience of ASD: It's a very labelling thing', 'I think they'd need to believe, believe what we're telling them', and 'Preparing for school and feelings about the future'***. Figure 5.1 provides an overview of the themes identified in the data.

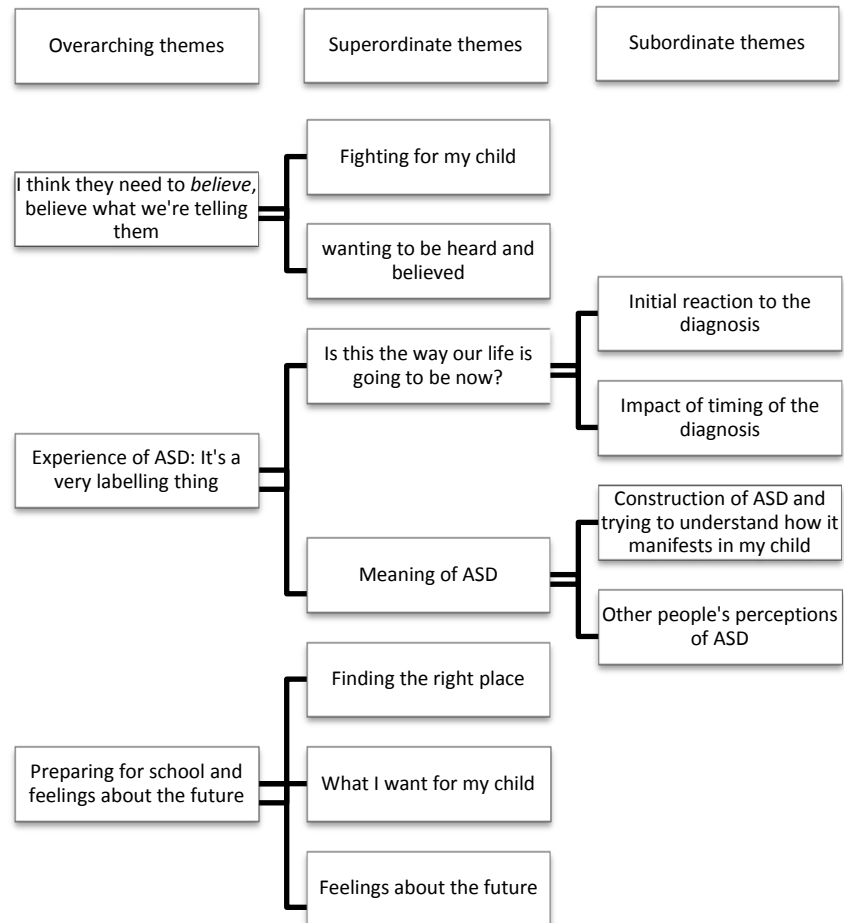


Figure 5.1 Overarching, superordinate and subordinate themes identified in the present study

5.2.1 Research question one: What are the experiences of parents whose children with ASD are starting school?

This research question was the primary question. In the following section, key findings from the literature and from the present study that related to the primary research question are summarized.

He has the difficulties diagnosed so we can help him not to be labelled and be called whatever you have and you know yourself kids can be cruel and labels stick (Olivia, P.55, L.1431).

5.2.1.1 Overarching theme 'Experience of ASD: It's a very labelling thing'

This overarching theme captured the participants' experiences of ASD and its meaning for them. It encompasses their feelings and experiences of receiving their children's diagnosis of ASD and reflects their concerns about stigma. Different strands to the experience of stigma were identified in this study as evidenced in the themes '**Experience of ASD: It's a very labelling thing**' and '**I think they need to believe, believe what we're telling them**'. On one hand, children were not stigmatised until they were given the diagnostic label of ASD; on the other hand, professionals and family members disputed the diagnosis because the children in question did not fit their conceptualisation of ASD. Similarly, professionals sometimes disputed the diagnosis, causing upset and concern for some participants. Among the professionals who did acknowledge the diagnosis, some were perceived by participants to either underestimate or overestimate the children's difficulties.

The experience of stigma was explicitly evident in the case of one child in the current study; Tony and Catherine described a difficult encounter with staff in one of their chosen mainstream schools. They felt Chloe was seen as a monster and a chore by school staff as evidenced in their transcript. They subsequently had the opposite experience in another school, where they were made to feel that Chloe was welcome. Hannah and Olivia expressed fears about stigma arising from the label and, for this reason, didn't want the diagnosis generally known.

Lilley (2012), in her exploration of the experiences of mothers of children with autism in Australia, found that stigma was a common experience for participants in her study; children with autism were stigmatized because of their condition and their mothers reported that they experienced stereotyping, discrimination, and efforts by school professionals to informally exclude their children. Participants in Lilley's (2012) study were noted to experience courtesy stigma, a stigma that has been described as experienced by people who are connected with stigmatized people. Lilley (2012) questioned commentators who maintained that stigma was no longer a major issue for people with disabilities. Findings from the current study corroborate some of Lilley's findings in relation to the experience of stigma but there are some differences. Participants in this

study were concerned about stigma from other parents, other children, and family members as well as from school professionals. In the overarching theme ***‘Experience of ASD: It’s a very labelling thing’***, two participants described concerns about stigma explicitly; they were anxious because they felt their children would be excluded from typical experiences should others find out about their ASD diagnosis. This was a factor in their choosing mainstream placements for their children. They wanted their children to have access to typical childhood experiences and didn’t want them to be segregated or treated differently because of their ASD. One participant spoke of seeing other children treated differently because of ASD.

A finding that was not described in Lilley’s (2012, 2014) studies was the experiences of participants of stigma within their extended families. Some participants felt judged by others and felt as though their parenting skills were being called into question and the children’s difficulties were due to poor parenting; participants described the experience of having family members discount the children’s diagnosis. Some participants felt that others judged them for receiving hand-outs and benefits from the government and even worried that people would say they had the children diagnosed just to access benefits. Stigma was not reported as an explicit concern for parents in the other studies reviewed in Chapter Two.

The experience of stigma and the feelings it engendered in participants could be said to relate to the proximal processes in Bronfenbrenner’s bioecological model (Bronfenbrenner & Morris, 2006). Participants were concerned about stigma and other people’s perceptions of ASD. Stigma could be seen to impact on the relationships that some participants had with family members and with others in the community, occurring at the level of the microsystem (within their own family of origin) and the mesosystem (in their relationships with professionals and others). Lilley (2012) also explored the issue of stigma at a macrosystemic level, whereby she maintained there was an ongoing debate about whether or not people with disabilities were still subject to stigma.

In the next section, the overarching theme ***‘I think they’d need to believe, believe what we’re telling them’*** is discussed in the context of the first research question.

5.2.1.2 Overarching theme 'I think they'd need to believe, believe what we're telling them'

This overarching theme represented findings relating to how participants felt about their interactions with professionals and being heard and believed by other people. In the present study, participants spoke of their experiences with professionals, which ranged from positive (as when Olivia and Maria called on therapeutic team members to support them) to negative (as when Tony and Catherine met with school staff who were not willing to admit Chloe to the school). Relationships, trust, and communication were important considerations for Maria, who spoke about working hard to build up communication and understanding with school professionals. For participants in Miles's (2012) study, relationships with professionals were seen as paramount in achieving a successful transition. These relationships featured important components such as trust, communication, support, and sharing of information and expertise. Participants in Miles's (2012) study sought the expertise of professionals to help and support them in decision-making around school placements but found that this was sometimes lacking. Trust was an important consideration for Hannah, a participant in the present study; she wanted someone to look after James when she wasn't there echoing one of Miles's participants who was looking for a second mother to mind her child in school. Participants in the present study felt that meeting school staff was very important and felt relief when school staff had desirable personal qualities such as being nice and gentle.

Participants in Miles's (2012) study talked about the importance of communication with educational professionals; communication was noted to alleviate anxiety for parents. Similarly, participants in the study conducted by Stoner et al. (2007) identified communication with school professionals as a vital link which was fostered by visiting school and meeting the teachers, and which facilitated preparation for the transition. Participants in Russell's (2005) study cited communication with school staff as an important factor influencing their expectations around their children's inclusion in school and an important means of facilitating their understanding of their children's conditions. Communication between preschool and kindergarten / school teachers was noted to be an important element of the transition process in the transition

process (Forest et al., 2004; Quintero & McIntyre, 2011), though meetings involving teachers did not always materialise. Communication between parents and school staff was a theme which was also identified and will be discussed in more detail in the context of the overarching theme ***‘Preparing for school and feelings about the future’*** below.

Lilley (2014) spoke of the power differentials that participants experienced in their interactions with professionals. In the present study, some participants, such as Maria and Olivia, spoke of feeling that school staff listened to professionals more than they listened to parents; this was also evidenced in the superordinate theme ***‘Fighting for my child’***. There was a sense of needing to fight for their children’s rights at times, whether to get understanding for the children, to get the right support, or to get the right school placement. This was echoed in Russell’s (2005) study where one parent talked about her battle with a preschool teacher to have her child’s needs understood. Olivia talked about having to adopt a different persona when negotiating with professionals around what Cormac needed. Maria was conscious of a difference between the educational level of professionals and her own educational level, which she found intimidating. Maeve was upset when her son’s diagnosis of ASD was called into question and worried that his support in school would be taken away. Professionals in the present study had some power over decisions made in relation to resource provision and access to school placements, factors which seemed to be outside parental influence or control.

In the Stoner et al. (2007) study, participants emphasised the importance of a child-centred focus on transitions. Parents of children with ASD in the study by Parsons, Lewis, et al. (2009) were significantly more likely to report concern that staff had expertise and knowledge of their disability than parents of children with other disabilities; this may have indicated an anxiety on their part that the children be understood. It is interesting to note that despite this, parents of children with ASD in the study by Quintero and McIntyre (2011) reported that they received less input and support around transitions than their counterparts whose children had other disabilities.

In the current study, the child-centred nature of the transition was bound up with the parents feeling understood themselves. As advocates for their

children, it was important that aspects of the transition were also parent-centred and that parents were heard, understood, and believed. There was a sense of parents struggling to be believed which was a key prerequisite for having their children's needs understood. As mentioned, some participants had to bring professionals in to talk with school staff about their children so the children's needs would be understood.

5.2.1.3 Overarching theme 'Preparing for school and feelings about the future'

Participants in the present study talked about their experience of finding the right school placement for their children and about their feelings about the future as evidenced in this overarching theme. They spoke of support they had received from professionals such as the children's HTs, MDT professionals and SENOs.

Miles (2012) talked about parents seeking support around the transition but that some parents found that professionals were reluctant to influence their decision-making and seemed to withhold their opinions on placement options. This contrasted with Lilley's (2014) findings that professionals vied to influence parental decision making around suitable educational placement leaving parents conflicted. The findings in the present study did not reflect a sense of professionals withholding information or being reluctant to give advice around placements for the majority; however, in Catherine and Tony's case, there had been differing opinions between professionals about the best place for Chloe. Her home tutor (HT) felt she would be able to manage in a mainstream school, whereas her MDT expressed the opinion that she should attend a special class. This had caused dismay for Catherine who wondered why the HT would say Chloe was able for mainstream if she wasn't.

In relation to transition practices, Stoner et al. (2007) emphasised the importance of planning for transition. Participants spoke of collaborating with professionals to this end. Transition practices were examined in detail by Quintero and McIntyre (2011) and Forest et al. (2004). Findings suggested that some standard transition practices did take place before children with disabilities started school but they were not always individualised to the child. Furthermore, key practices in the transition process such as meetings between

preschool and kindergarten teachers did not always take place because of a lack of time.

Stoner et al. (2007) found that participants focused on horizontal transitions as these have a significant impact on the lives of children with ASD. Horizontal transitions were not explicitly mentioned in the current study but participants did implicitly mention children's difficulties with horizontal transitions such as the children's difficulties coping with change. Olivia found that she had to support school staff by preparing and giving them information and materials to support Cormac starting school and help him cope with horizontal transitions.

Transition practices discussed in the current study by all participants included visiting schools, providing information for the new school, and trying to prepare the children for the transition. Russell (2005) reported that some participants found the process of visiting schools very difficult though this was not further explored in the study. Maria spoke of the need for good communication between parents and professionals at the start of school so that the professionals would understand her methods and her children's needs. Hannah spoke of her wish to communicate with James's new teacher and how difficult it was to step back and wait to be approached by the teacher.

5.2.2 Research question two: What goals and options do parents feel they have around their children's education?

This research question explored the goals and options that parents of children with ASD have around their children's education. The themes discussed in the sections below encapsulated participants' expressions of their goals and options for their children's education.

Please God, let him just get through school, go to college and you know, not be worried (Hannah, P. 21, L.628).

5.2.2.1 'Preparing for school and preparing for the future'

In the present study, the process of getting the diagnosis of ASD for their children, whether the outcome had been anticipated or not, had direct consequences for the lives of participants and for their children's lives. Having a

diagnosis of ASD meant that life changed in some way and the future was less certain. In some cases, such as Olivia's, there was an expectation of change which did not materialise, for example, there was a question that her family might have to move home to be near a specialised school placement when Cormac got his diagnosis but this didn't actually happen. For Catherine and Tony, there was a shock and a sudden entry into the world of special preschools and special classes. Catherine spoke of things slipping away as if the world had changed and she could see a different future for Chloe full of horrible things that might never happen. For these participants, having the diagnosis meant access to resources and support but it also meant entry into an unfamiliar and sometimes frustrating world of special education, special needs, and ongoing worry about the future.

For some of the participants in Miles's (2012) study, educational options and goals were bound up in the realisation of their children's diagnosis; some participants were still going through the process of coming to terms with the diagnosis, understanding their children's needs, and considering the long-term implications of ASC. Participants were struggling with making decisions about education that would impact on their children's futures. They spoke of the importance of early identification of their children's needs because they needed to get the appropriate support and resources for school. Participants talked of their difficulty obtaining a statement of educational needs for their children and how this was a cause of concern and stress. In Russell's (2005) study parents benefitted from having a statement of educational needs; it helped to clarify their expectations of their children's issues and the support they would receive in school.

Participants in the current study found the decision-making process around education was stressful because of the impact this would have on future schooling and later in life. Participants were worried they would make decisions that they would regret later on. In comparison, participants in the study by Parsons, Lewis, et al. (2009) did not report high concerns for their children's continuation in education but did worry that they would not get employment in adulthood.

Lilley talked of a "highly fractured educational field" (2012, p. 518) where participants were conflicted and bewildered by contradictory educational

policies and practices. In the present study, the fragmentary nature of educational provision for children with ASD is evident in the dearth of provision for preschool children with ASD and in the uncertainty around school placements. Chloe missed a place in a special preschool because of her late diagnosis and Catherine and Tony had subsequently been very worried that Chloe would not have access to a suitable special class. SNA support was not guaranteed for children with ASD who did not have significant care needs and so Hannah was struggling with the fact that James did not have an SNA. Maria worried that school staff would not understand Paul's needs as in the past, when she had to bring in professional support to back her up. Despite the timing of diagnoses, the apparent lack of appropriate places, fears about lack of support, and the seemingly ad hoc manner in which places became available, all participants had found places for their children which they felt were suitable at the time of their interviews. This echoed findings in Miles's (2012) study where the majority of parents were satisfied with their children's school placement and in the study by Parsons, Lewis, et al. (2009) in which the majority of participants were positive about school placement.

In relation to concerns about the future, Miles (2012) found that worry didn't diminish following the transition for participants in his study but continued into their children's first year in school. There was a sense from participants of their anticipation of being lifelong advocates for the children. In Russell's (2005) study, the participants' expectations had been broadly realised by the end of the first year in school. Participants had a better understanding of their children's needs and conditions and of the educational system. Findings from the current study indicate that participants think a lot about the future, both their own, and their children's. As in Miles's (2012) study, participants spoke about trying to find school placements for their children, trying to understand their children and how ASD manifested for them, and trying to get others to understand their children.

Thinking about the future and the process of securing an appropriate educational placement for their children with ASD yielded a variety of experiences for participants. Finding the right school was identified as an important issue for all participants. Three of the children were going to attend mainstream school and two were going to attend special classes attached to

mainstream schools. Having a diagnosis of ASD set the context for the children's school placement in most cases, for example, the diagnosis meant that children could access resources, support and, where necessary, specialised educational settings. Finding the right school placement had not been an automatic process, however, and participants had taken a number of factors into account when choosing schools. Among these factors were the child's ability and needs, the availability and suitability of the placement, their feelings about school staff they had met, and concerns about stigma. Luck also seemed to be a factor in finding the right place in the cases of participants such as Hannah, Catherine, and Maeve.

In the present study, participants had access to SENOs, part of whose role includes recommending resources for children attending school and supporting parents in finding suitable school places. Four of the participants spoke directly about SENOs with whom they had contact; three participants commended their contact with SENOs who, they felt, had been helpful and open; one participant had a negative experience with the SENO she met because she felt the SENO had been patronising and had minimised her son's needs when she said he seemed like any other child of his age.

The prior experience of participants who had older children with ASD appeared to be a consideration in their choice-making. Hannah felt her two children were very similar; her older boy had done well in school and so she had chosen a mainstream placement for James. In Maria's case, her older son attended a mainstream school which had worked out reasonably well for him despite many difficulties and so she felt confident that Paul would do well if he had the right support. Maeve had seen the difficulties faced by her older son in school and consequently felt that the ideal place for David was in a special class. In Russell's (2005) study, the group of parents of older children who provided advice and support in the study had concerns about the expectations of the sample group of participants. It was felt that participants in the main had little understanding of the information they were given about their children, had little experience of disability and did not have experience of the special education system. These factors impacted on the expectations of participants, sometimes leading to negative outcomes such as disappointment in the case of at least one participant.

Among the features of schools that were important to participants in the present study were friendly, welcoming staff; small size; safety, and adult support. Of interest is that participants did not mention staff having experience of ASD or the use of ASD-specific strategies as necessary conditions in their choice of school placement. This compares to the findings in the study by Parsons, Lewis, et al. (2009) where participants were concerned that staff have expertise and knowledge around ASD. To participants in the current study, the personal qualities of people working with their children and the relationships they could have with them were important considerations.

This study explored the goals parents had for their children's education. These goals depended to a large degree on the children's ability and issues. Participants were primarily concerned that their children would be understood by educational professionals and others. Olivia and Hannah, whose children were attending mainstream school, were concerned that they would fit in with other children. Hannah talked about her hope that James, who was academic, would be able to go to college. Maeve, Catherine and Tony, were very concerned about safety and hoped that the school staff would ensure the children did not elope. Maeve felt her children were better off in special class because other children could be so cruel. She expressed the desire that there would be a special school for children with high functioning autism because their social difficulties and their vulnerability made them targets for bullying and teasing. Maeve was not concerned about academic results as long as her children were happy.

There was a sense that for participants, their goals for their children's education were as much about safety, happiness, and social inclusion, as academic success, as evidenced in the following extract:

You want him to be able to go the shop, do you know, ride his bike, do whatever, like... you just want him to live a normal life (Olivia, P.34, L.828).

5.2.3 Research question three: What kinds of feelings do parents have around their children starting school?

That's what you're up against: The system which is a set of rules and you're dealing with parents, who are obviously (coming) from the emotional and just wanting the best for their children (Olivia, P.32, L.782).

This question aimed to explore the kinds of feelings participants had about their children starting school. Feelings that parents expressed in their interviews are reported in the three overarching themes ***'I think they'd need to believe, believe what we're telling them'***, ***'Experience of ASD: It's a very labelling thing'***, and ***'Preparing for school and feelings about the future'***. Participants in the current study described a variety of feelings about their children starting school, about how the children were treated by other children, and about the future for themselves and their children. Feelings about the children starting school arose from such experiences as the search for an appropriate school placement, finding an appropriate school placement, and feelings about the future. Feelings identified in the study included hope, annoyance and frustration with professionals, uncertainty, arguing with self, relief, worry, panic, concern, and intimidation. These are described in more detail in the following sections.

5.2.3.1 'Search for an appropriate school placement'

Participants talked about having to fight to secure services and support for their children. The nature of the children's difficulties impacted on their decision-making; priorities depended to some extent on the severity of the children's needs such as sensitivity to noise and tendency to elope, for example, Maeve had been very concerned at the prospect of David attending a mainstream class; Catherine talked about panicking and having a sinking feeling when she had no placement for Chloe.

Lilley (2012, 2014) reported that participants in her study experienced stigma and conflict. She reports that they felt lost, powerless, uncertain, perplexed, confident, emotionally exhausted, and unsure in negotiating their children's transition to school. There are similarities between the feelings expressed by participants in her study and those experienced by participants in the current study.

5.2.3.2 'On finding an appropriate school placement'

Hannah talked of being glad that she had a choice of sending James to mainstream so he wouldn't be stigmatised by attending a special class though she was still uncertain whether it had been the right choice and felt it would be her fault if things went wrong. She found that having to write down James's needs and issues for the SENO had been very hard. Catherine described being really happy after meeting the school principal who offered Chloe a place in a special class. She and Maeve both described the school placements the children eventually got as "heaven"; the special classes were the ideal options for their children's education and gave participants a sense of peace and relief.

Maria was unnerved about Paul starting school because she felt that his success would depend on the support he was given there and she had **no** control over this.

5.2.3.3 'Feelings about the future'

Participants in the current study talked about their feelings about the future. Tony seemed confident that Chloe would overcome her difficulties but Catherine was very worried about Chloe's issues with noise sensitivity and eloping, and may have felt things would get worse in the future given that the issues with noise had been a sudden recent development. The wish for Hannah and Olivia was that their children would fit in and have friends. They worried about their children's social skills. Olivia talked about needing to take things one day at a time because looking at the bigger picture was overwhelming while Hannah said she always found herself looking to the future, and it seemed from her interview, that she often worried about the future. Maeve talked about trying to get fit again as if she was slowly regaining some control over her life and I had the impression that she was hopeful about the future; she described her relief that David would be in the right place.

Participants in Miles's (2012) study expressed a variety of feelings about their children's transitions to school which were connected to coming to terms with the children's diagnosis of ASD and with their anticipation of how the future

was going to be. Feelings described in his study included upset, worry, hope, and acceptance.

Stoner et al (2007) explored participants' concerns and perspectives but did not focus on their feelings in an explicit manner. Nevertheless, extracts from their study indicate that participants expressed feelings such as hope, optimism, and nervousness. One parent described his child's future transition from school to the adult world as his "nightmare" (p. 32).

Having discussed the relationship of the findings to the research questions and the literature, the next section presents the relevance of the theoretical framework.

5.2.4 Relevance to theoretical framework

The bioecological model (Bronfenbrenner, 1986; Bronfenbrenner & Morris, 2006) has been used as a theoretical framework in research on children's transitions to school. Studies have usually placed the child at the centre of the model within the microsystem of the family. In this study, I used a different lens to place the parent at the centre of the bioecological framework and to view the parent as a developing being in their own right. Phenomenological considerations and the context in which people develop are both important features of the bioecological model (Bronfenbrenner & Morris, 2006). The conceptualisation of a dynamic interplay between subjective and objective experiences allowed participants' concerns to be put the fore in this research; this facilitated an in-depth examination of participants' experiences, feelings, and perceptions during the process of their children's transitions to school and their engagement with professionals and other people in their lives.

Placing the parent at the centre of the model may represent a departure from the usual use of the model in the study of children's transitions to school but I felt that using the bioecological theoretical framework would provide a means of shifting the focus of the research onto how parents experience the process. Russell (2005) used the ecological model to frame findings at four of the levels of interaction (micro, meso, exo and macro) described by Bronfenbrenner (1977), acknowledging the participant's engagement in the different contexts and processes of transition. In the current study, the parent and child were centrally placed to highlight their unique relationship and

connectedness. As the child's primary carer and advocate, what happens for child affects the parent in the transition process.

The framework I used focused on the key elements of Bronfenbrenner's model (Bronfenbrenner & Morris, 2006); process, person, context, and time. This conceptualisation allowed me to explore the individual participant's phenomenological experience (person) of their child's transition (process) across a number settings (context) in the chronosystem of the transition (time). While I found considerable variation amongst the experiences of participants, the framework allowed for this variation, and for key themes to be developed that represented areas of common experience.

5.3 Critical evaluation of the research project

This section contains a critical review of the current research study, including a critique of the method I chose, and the quality and rigour of the research process. Reference is made to my role as researcher, to ethical considerations, power relations, and to reflexivity. The key distinctive contribution of this study to the literature is discussed and recommendations are made around areas for future research. Implications for EP practice are discussed.

5.3.1 Suitability of the method

IPA was the method I chose for the purposes of examining the topic under review, which involved gaining insight into people's experiences. This method fits with the underlying epistemology of the research; critical realism (Fade, 2004; Mertens, 2010) and the nature of the research questions (Smith & Eatough, 2006). IPA allowed the research questions to be explored in an idiographic manner (Smith et al., 2009) which was a requirement of the study. IPA also allowed a cross-case analysis to be undertaken so that the views of a number of participants could be elicited and areas of divergence and convergence could be explored (Smith et al., 2009). I consider that IPA was a suitable method for exploration of the topic under examination. The research questions were addressed and I identified a number of findings which have added to previous findings on the subject.

5.3.2 *Quality of the research*

In this section, I discuss issues relating to the quality of the research in the current study. I used Yardley's (2000) criteria for quality as a guide as these comprise a comprehensive list of indicators of quality and rigour in qualitative studies. Yardley (2000) listed the following criteria which will be discussed in turn below: sensitivity to context; commitment and rigour; transparency and coherence; transferability, reliability, and validity, and impact and importance. I consulted key commentators in the field of interviewing and analysis (Kvale & Brinkmann, 2009; Smith et al., 2009; Willig, 2012) throughout the study to ensure a rigorous approach. Therefore, issues such as my role as researcher, ethical considerations, power relations between myself and participants, and reflexivity were considered throughout the study. These features will be discussed below.

5.3.2.1 *Sensitivity to context*

Sensitivity to context was reflected in the choice of research topic; I was familiar with the topic and context in which the study took place. Furthermore, I was familiar with the types of issues experienced by participants and so was able to appreciate the topic in some depth. I adopted a sensitive approach in the selection of participants and took care that they would not experience distress. In addition, I selected participants on the basis that they were experts on the topic, that they were unknown to me, the researcher, and that they were comfortable being involved in the study.

5.3.2.2 *Commitment and rigour*

Commitment and rigour were demonstrated in the manner in which the study was carried out. I gave a full commitment to undertake the study to its completion and to address issues relating to quality. I took a rigorous approach to the design of the study, including selection of the most suitable method to address the research questions. Furthermore, I applied the method with care, for example, I consulted and followed expert guidelines and made reflexivity manifest at each stage of the study (Please refer to Chapter Three).

5.3.2.3 Transparency and coherence

I made every effort to be explicit about my own role in the study and about my role in interpretation. I provided evidence for each research claim made. A sample of an interview transcript has been made available for scrutiny in the appendices as have the coding and development of themes. I made the nature and focus of the study explicit to participants and this has been outlined in detail.

I made every effort to explain the findings in a coherent manner and to refer to the literature on the topic. I have explained and detailed abstract features of the analysis, such as the hermeneutic process, to show the reader how the process was undertaken and how interpretation was carried out. I have provided comprehensive information on topics, including the context and the findings, in the appendices to supplement the information given in the main text.

5.3.2.4 Transferability, reliability and validity

IPA is a method which is idiographic and inductive (Brocki & Wearden, 2006; Smith & Eatough, 2006); the principal aim is to perform an in-depth analysis and interpret individual experiences, not to make general claims. It is more accurate to say that findings can be transferred across cases in an IPA study rather than generalised (Smith & Eatough, 2006; Smith & Osborn, 2003).

In the present study, I analysed experiences and phenomena in detail, examined areas of convergence and divergence and conducted a cross-case analysis. Examining how the findings in this study fit into the overall literature is an attempt to find out how the experiences of participants in this study transfer across areas of common human experience; by examining individual experiences of phenomena, I built up a case-by-case picture of particular phenomena (Smith & Eatough, 2006). I made links to similar research studies and discussed areas of similarity and difference to build up a picture of parents' experiences around their children with ASD starting school.

Qualitative studies do not aim to fulfil objective commitments to validity and reliability; validity can be measured by the expertise of the researcher and the extent to which the study investigated what it set out to investigate. Reliability can be measured by efforts towards achieving consistency and trustworthiness (Kvale & Brinkmann, 2009). I made efforts in this study to apply

the most appropriate research method to the research questions in a rigorous fashion.

5.3.2.5 Impact and importance

This study adds to the literature on the topic. Some new, and hopefully useful, findings have been identified and described in detail. These findings are summarised in section 5.3.3.

The findings from the study were presented at the Psychological Society of Ireland's annual conference in 2014. I intend to write up the study as a journal article and submit it for publication in a peer-reviewed journal. I will share the findings with colleagues in the ASD service at a journal club meeting. The information will be used to inform practice around transition support for children with ASD and their parents. I will share findings with education professionals who attend training workshops on children starting school run by the ASD service. I will share the findings with the participants in this study.

5.3.2.6 Role of researcher

I took care to consider my role as researcher at each stage of the study from the design to reporting of the findings. Participants were selected so there would be minimum impact of my day job as a psychologist on the findings.

I gave due note to the opinions of commentators such as Kvale and Brinkmann (2009) who maintained that the interviewee's statements were not collected, they were co-authored; that the fixed written form took over as the original face-to-face interaction of the interview faded away. Therefore, I attempted to be explicit about my role in the production of the findings.

5.3.2.7 Ethical considerations and power relations

I consulted ethical guidelines from the BPS, the PSI and UEL and applied these throughout each stage of the study, from the design, the selection of participants, through the interviewing phase, the treatment of data, to the writing up stage. Participants were guaranteed anonymity and confidentiality. I considered potential distress and guaranteed participants the right to withdraw at any time during the study or afterwards, prior to compilation into a report. I

informed them verbally, and in writing, of the aims of the study and the extent of their participation. I offered follow up support if participants experienced distress or had questions about the study.

In a study of this kind, there can be questions about power relations between researcher and researched. Questions can arise about who owns the meanings of what is found and therefore, any resulting power asymmetry should be examined (Kvale & Brinkmann, 2009). In this study, I explained to participants that I was a researcher and I emphasised their key roles as informants and experts on the topic under review. In the analysis and compilation of findings, I have been explicit about my role in interpretation and my role in co-construction of the findings while the principal authority of the participants is acknowledged.

5.3.2.8 Reflexivity

I attempted to adopt a reflexive approach in this study. This was actualised by considering reflexivity at each stage from the thematising stage to the writing up phase. I had supervision to check my method of interpretation and to help me move from descriptive thematising to interpretative analysis of findings from the interview transcripts. I initially questioned whether I had the right to interpret the participants' transcripts but adopted a position of discomfort (Pillow, 2003). A reflexive log was used to aid in adopting a reflexive approach.

As mentioned previously, an imaginary letter was written to participants to explain that the findings were a product of my interpretation of their words which I acknowledged may not reflect their intentions. Taking ownership of my role in co-creating the findings allowed me to go beyond the descriptive, manifest interpretation and make step towards more in-depth interpretation.

5.3.2.9 Limitations

Limitations in this study include the scale of the study which is small and particular. Results cannot be generalised though they can be transferred across similar samples. Sampling was purposive of necessity and participants were self-selected which may impact on the transferability of findings; it is possible that participants represent a highly motivated group of people which would

impact on applicability of findings across other samples. The context of the study may limit its applicability to other settings, for example, Lilley (2012, 2014) had different findings in a similar sample of participants.

My role as researcher must be examined as it possibly impacted on my interaction with participants, the nature of the interviews, and the analysis and interpretation of findings. Lilley (2012) maintained that her insider perspective enabled her to access the world of her participants; if she had been a professional, she doubted whether she would have had the same access; therefore, it must be considered that knowledge of my role as a professional may have impacted on how participants experienced the interviews and on the answers they gave.

The very nature of the method, IPA, has implications for the role of the researcher who is considered a tool in the study. The end result is an account of what I think the participant is thinking; analysis in an IPA study is subjective and therefore, truth claims are tentative (Smith et al., 2009). Furthermore, IPA examines people's perceptions of events which may not reflect accurate occurrences. These factors may be considered limitations of the method employed.

5.3.3 Unique and distinctive contribution

In conducting a study of this type, it is useful to have a knowledge of ASD and educational and health systems. Furthermore, it is necessary to have sensitivity to the issues that impact on these participants. I had experience in the area and experience of conducting research with parents of children with ASD which proved advantageous. Having contacts with professionals in different agencies was most useful because it was difficult to find participants who met the inclusion criteria and who were able to participate in the study. Other professionals assisted in the identification and selection of potential participants.

The findings in this study yielded an in-depth insight into the experiences and perceptions of parents whose children with ASD were starting school. In contrast to the literature reviewed, the present study offers an interpretative, hermeneutic analysis of participants' experiences. Gaining an insight into the salience of individual parental experiences and concerns addresses a gap in the literature. The findings from this study corroborate some of the findings from

previous studies, such as the experience of stigma and the need for collaboration with professionals and understanding of the child.

The current study offers additional knowledge to the findings from previous studies including the experience of stigma from family members; the fear of children being stigmatized by others leading to social exclusion; the tendency of some professionals to overestimate the coping abilities of intellectually able children with ASD; the manner in which the construction of ASD leads some family members and professionals to deny the existence of ASD in some children; the impact of the timing of the diagnosis on the child's access to appropriate places in the Irish context; the impact of the diagnosis on the participants' experience of the education system; the desirable qualities of school staff and the impact of staff who were gentle, kind, and nice; parental concerns about safety, and an insight into what life in general is like and how difficult it can be for parents in this situation. School choice involved considerations such as safety, social inclusion, and freedom from bullying. Securing a school placement sometimes involved a sense of participants having to fight and struggle with the professionals and the system. Two participants described the impact of their children's elopement on their lives and on their choice of school placement.

The label of ASD seemed to be more of an issue for other people than were the children's characteristics and personal attributes. Participants feared that the label had the power to change how people saw their children even though the children hadn't changed by virtue of being diagnosed. There was a sense of the label taking away natural privileges that the children had such as being treated like everyone else, being included in peer activities such as birthday parties, and visiting other children's houses to play.

5.4 Conclusion

In this study, my main aim was to add to the literature on the experiences of parents whose children with ASD were starting primary school. The research questions have been addressed in this study and I have described the answers to the questions in the sections above. Findings in this study reflected what has been said in the literature and have added to what has been found previously. In the sections below, further research questions are discussed, the relevance

of the findings to the work of an EP are outlined, and outcomes and implications from this study are presented.

5.4.1 Further research questions identified

An interesting finding from this study was the gap revealed in the literature around what is known about the experiences of parents of typically developing children who are starting school. Finding out about the experiences of parents of these children would be a suitable topic for further research. Comparing the transition experiences of parents of children with ASD and parents of children who are typically developing would also be of interest to EPs and other professionals.

5.4.2 Relevance to work as EP

An exploration of parents' perceptions and feelings around their children with ASD starting primary school is an area that merits investigation as it is important for professionals, service providers, and policy makers to be aware of the views and experiences of this distinct population. Given that a literature search on the subject revealed a dearth of information on parents' unique perspectives on the topic, it is envisaged that this study will give greater insight into the particular concerns and experiences of parents in this situation.

This research complements existing practices that support children with ASD and their families around the transition to primary school. In Ireland, the Special Education Support Service (SESS) which operates under the DES, has developed a continuing professional development programme for teachers to support children with autism as they move between school settings. Entitled Supporting Children with Autism as they Transition through Education, the course acknowledges the importance of including parents in the transition process by providing strategies on facilitating good communication with home.

In the UK, Stobart (2012) has compiled a transition toolkit which offers practical strategies to parents and professionals to support children with ASD starting school. Transition teams composed of parents and relevant professionals are recommended to ensure a comprehensive approach the move. The Inclusion Development Programme (AET, 2009) is an interactive

resource for educational professionals which advocates working closely with parents to ensure successful inclusion for children with ASD. The National Autistic Society (NAS) runs a number of programmes for parents and professionals to support understanding around the needs of the child with ASD. These include the Early Bird (Shields, 2001) and HELP programmes, the aims of which are to equip parents with the necessary knowledge to support their young children.

In 2012, the All Party Parliamentary Group on Autism, published a report, *Reforming the System for Children with Autism* (NAS, 2012). The report introduced findings from a public survey as well as expert evidence from professionals, parents and young people. It offered key recommendations to support individuals with ASD in maximising their potential. Fewer than half of parents and young people interviewed thought they had enough involvement in shaping the support the child got at school; 30% of teachers agreed. 94% of parents thought they should be more involved in school. This survey shows that more needs to be done from the parental perspective to include parents in their children's education. Findings from in-depth studies such as the present one could help illustrate the experiences and perceptions of parents and demonstrate to professionals the need for parental involvement in their children's schooling.

It has been established that the start of school is a time of key importance for all children, including children with ASD. EPs have a potentially key role in supporting children with ASD and their parents in the transition process. Conn-Powers, Ross-Allen, and Holburn (1990) saw a need for a school transition facilitator who would support children and their families during transition, liaise between early education and formal school settings, co-ordinate transition planning, and ensure the goals and priorities of the family were included in the process. They viewed the school psychologist as an important team leader in supporting kindergarten transition for children with special needs. The findings in this study illustrate the difficulties that parents can face as their children start school. By giving professionals insight into parental concerns around such topics as stigma, greater understanding could be fostered, thereby facilitating effective communication and minimising parental stress. Section 5.3.3 provided an outline of the unique contribution of

this study; given the constraints on EPs in terms of time and resources, the findings could be disseminated to other relevant professionals who would take on the role of advocate for the child and family, communicating their issues and needs to others in the transition process and making sure they are included, supported and heard in the process. EPs could be involved in providing training to other professionals in relation to this advocacy role.

5.4.3 Outcomes

The chief outcome of this study is the increased knowledge of how parents of children with ASD experience their children's transition to school. According to Stoner et al. (2007) listening to parents, acknowledging the experiences parents have acquired by interacting with their children and incorporating parental suggestions into the educational program is essential when managing transition issues. In this study, parents were asked about their experiences and it is hoped this will inform practice to make their experiences better. This study identified how parents feel and has shed light on the choices parents make around their children's school placement and what they have to do to get them there.

5.4.4 Implications

I make a number of recommendations based on the findings in this study. The following points should be considered by policy makers and professionals in health and education:

Transitions to school for children with ASD should be parent and child-centred. Parents have detailed knowledge of their children and should be central in the transition process. Children with ASD are very different to each other; their strengths and needs may not always be obvious. Their parents are informants and advocates and should be consulted and have their intimate knowledge and views valued.

Professionals should be aware of the feelings parents have about their children starting school. They may be experiencing worry, uncertainty, and fear. They may also be experiencing relief and hope.

Professionals should be aware of the difficulty and uncertainty parents face in choosing and finding appropriate school placements for their children.

The child's diagnosis with ASD may entail a sudden entry into an unfamiliar world of special education and bureaucracy. Parents need information on the school system and the support available. Parents value having professionals such as SENOs to advise and support in finding school placements.

Dealing with the child's diagnosis can take time and parents often have to act quickly after the diagnosis to secure appropriate placements and support which is stressful and leaves little time to get used to the diagnosis. Parents may not have told many others about the child's diagnosis so telling school staff may be a big step for them. They may feel judged and blamed around the child's diagnosis, complicating their feelings.

The impact of stigma and the label of ASD can cause worry and can impact on parents' choice of school placement. Parents worry that stigma will cause exclusion and segregation. They are aware that their children may be vulnerable to bullying. Parents worry about their children's social skills and their ability to fit in with other children. They worry about how their children will manage socially in the future. Social achievement may be more of a concern than academic achievement. Professionals should be sensitive to the parents' considerations in choosing school placements.

Professionals should be aware of power differentials with parents

Parents sometimes experience a power differential with professionals and can find the experience of dealing with professionals intimidating, unnerving, and a battle. School staff who are nice, gentle, and kind inspire parents with confidence and hope. Parents value access to, and communication with, educational staff.

Parents have very different experiences and perspectives; It is important to recognise the range of feelings they may have in relation to the transition process. They may have had difficult experiences finding appropriate places and dealing with professionals in previous encounters.

School staff should consider meeting with parents before and after the transition

Parents value contact with school staff. Fostering understanding around the child's strengths and needs can facilitate a smoother transition for the child. It would be useful for school staff to meet with parents before and after the transition to school to discuss concerns and strategies, for example, around horizontal transitions and to put support in place to ease the vertical transition.

Key liaison person

A key person, such as an EP, should have the role of making sure parents are consulted and included in transition planning and process.

Professionals should understand the complexity of the lives of parents of children with ASD

In this study, three of the participants had older children with ASD. Having one child with a disability can be challenging for families; having more than one child with a disability can increase the challenges parents face. It would be useful for professionals to be aware of the unseen difficulties that many parents experience and to bear this in mind in their dealings with parents.

5.5 Summary of Chapter Five

Chapter Five began by relating the research questions to the findings in the present study. The research aimed to explore the experiences, perceptions, goals and feelings of parents whose children with ASD were starting school. The findings were summarised in the overarching themes **'Experience of ASD: It's a very labelling thing', 'I think they'd need to believe, believe what we're telling them', and 'Preparing for school and feelings about the future'**. In section 5.2, the research questions and their relationship to the findings were explored. Findings indicated that the child's transition to school can be a stressful time for parents. They may have to grapple with a recent diagnosis of ASD in addition to finding a suitable school placement. Issues such as stigma were concerns for some of the participants in the present study, a finding that was echoed in other research. Stigma shaped how some family members and professionals reacted towards the children, complicating the

relationships participants had with other people and impacting on the choice of school placement. Participants spoke of their conceptualisation of ASD and their attempts to understand how it manifested in their children. Being listened to and believed was important to participants. Their desire for good communication with professionals echoed findings in other studies, where it was seen as important in facilitating smooth and successful transitions. Findings in the present study suggested a sense of participants being in conflict with the educational system, and with themselves, at times, in the struggle to secure resources and appropriate placements for their children. It was notable that in the end, all of the participants in this study were satisfied with the child's proposed schooling option. This satisfaction mirrored findings in some other studies. Participants spoke of desirable qualities in educational staff, including the wish that they would be kind and nice. Feelings that participants expressed about the transition included worry, being unnerved, and hope. Participants were relieved when they eventually found the right place for their children, though some were anxious about how the children would get on in when they got there.

In contrast to other studies, this study focused explicitly on the experiences and perceptions of parents whose children were about to start school. Findings were analysed in detail and it was felt that overall, the research questions were answered; parental experiences, goals and feelings around their children's transition to school were elicited.

The relevance of the theoretical framework used to frame the study was discussed in section 5.2.4. Bronfenbrenner and Morris's (2006) bioecological model fit with the epistemology and research paradigm in this study and provided a means of focussing on the participants' experiences in the context of the transition. The method, IPA, allowed an in-depth exploration of participants' experiences and enabled a cross-case analysis of their experiences. IPA fit with the theoretical framework and the philosophical underpinning of the study and was found to be a rigorous means of answering the research questions.

Issues relating to quality in the current study were discussed in section 5.3.2. Every effort was made to adopt a rigorous approach to conducting the research by following best practice and ethical guidelines from professional bodies, consulting with Yardley's (2000) criteria for quality in qualitative

research and with expert guidelines, by adopting a reflexive approach and consulting with supervisors. Limitations of the study and of the method were also outlined in the section. As this study was conducted on a small scale and in an idiographic manner, findings cannot be generalised but it is hoped that the findings have reflected participants' accounts and have added to the literature on parents' experiences of this life-changing event.

In section 5.4, the relevance of the study to the role of the EP was described. EPs could disseminate the findings in this study to other professionals to highlight the importance of including parents in the transition process; to show how stressful the process is for parents, and to facilitate effective communication between parents and school staff. EPs could be involved in training other professionals to take an advocacy role for parents in the process. Further research could be conducted into the experiences of parents of typically developing children who are starting school as a literature review revealed a dearth of research into this topic.

The outcomes and implications of the present study were outlined in sections 5.4.3 and 5.4.4 respectively. The findings in this study complement initiatives undertaken by agencies in, for example, Ireland and the UK, which offer advice and outline strategies to support parents and professionals in ensuring smooth and successful transitions for children with ASD. A number of recommendations were made in this study which could help professionals to take a more supportive approach to parents whose children with ASD are starting primary school.

I would like to conclude this chapter with a quotation from Maeve's interview which sums up some of the feelings participants expressed in relation to how they were perceived by others. Her quotation eloquently illustrates the additional pressures experienced by parents as they engage with other people in other systems:

I think they'd need to believe, believe what we're telling them, not look at us as if that we're making this up on them. They make us feel as if we're bad parents, do you know, and we could be the worst parents in the world and we still wouldn't be going through this (Maeve, P.33, L.819).

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Appendix 1

Literature search using EBSCO database

Database	EBSCO
Search term 1	"Children with autism starting primary school"
Initial results: First 20 articles surveyed; Relevant topics N = 1	6. Lilley, R. (2012). It's an absolute nightmare: Maternal experiences of enrolling children diagnosed with autism in primary school in Sydney, Australia
Search term 2	"Children with ASD starting primary school"
Relevant topics N = 0	
Search term 3	"Children with autism transitioning to primary school"
Relevant topics N = 2	7. Denkyirah, A.; Agbeke, W. (2010). Strategies for transitioning pre-schoolers with ASD to kindergarten. 8. Beamish, W.; Bryer, F.; Klieve, H. (2014). Transitioning children with autism to Australian schools: Social validation of important teacher practices.
Search term 4	"Children with ASD transitioning to primary school"
Relevant topics N = 1*	Denkyirah, A.; Agbeke, W. (2010). strategies for transitioning pre-schoolers with ASD to kindergarten*
Search term 5	"Parents experiences of transitions and children with ASD"
Relevant topics N = 0	
Search term 6	"Parents experiences of transitions and children with autism"
Relevant topics N = 0	
Search term 7	"Parents experiences and children with autism starting school"
Relevant topics N = 2	9. Keenan, M.; Dillenburg, K.; Doherty, A. (2010). The experiences of parents during diagnosis and forward planning for children with ASD. 10. Stoner, J.; Jones Bock, S.; Thompson, J. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals.
Search term 8	"Parents experiences and children with ASD starting school"
Relevant topics N = 1*	Stoner, J.; Jones Bock, S.; Thompson, J. (2005)*
Inclusion criteria:	<i>Exploring the experiences of parents of children with disabilities and / or ASD starting primary school; sufficient information on method, outcomes, and quality; contextual, theoretical and conceptual information to support the exploration of the topic under review provided; peer reviewed; 2004 – 2014</i>
Exclusion criteria:	<i>Not in English; Published prior to 2004; that they did not adequately meet the inclusion criteria as described above; referring to transitions from to secondary school or to adulthood; descriptive or theoretical arguments.</i>
Suitable references for review: N = 1	1. Lilley, R. (2012)

* found in previous search

Literature search using Google Scholar

Database	Google Scholar
Search term 1	"Children with autism starting primary school"
Initial results: First 30 articles surveyed; search stopped at 30 as results were not relevant to topic; Relevant topics N = 1	2. Stoner, J.; Angell, M.; House, J.; Jones Bock, S. (2007). Transitions: Perspectives from parents of young children with autism spectrum disorder (ASD).
Search term 2	"Children with ASD starting primary school"
Relevant topics N = 0	
Search term 3	"Children with autism transitioning to primary school"
Relevant topics N = 2	Stoner, J.; Angell, M.; House, J.; Jones Bock, S. (2007)* 3. Stoner, J.; Jones Bock, S.; Thompson, J. (2005). Welcome to our world: Parents perceptions of interactions between parents of young children with ASD and education professionals.
Search term 4	"Children with ASD transitioning to primary school"
Relevant topics N = 2*	Stoner, J.; Jones Bock, S.; Thompson, J. (2005)* Stoner, J.; Angell, M.; House, J.; Jones Bock, S. (2007)*
Search term 5	"Parents experiences of transitions and children with ASD"
Relevant topics N = 5	Stoner, J.; Jones Bock, S.; Thompson, J. (2005)* Stoner, J.; Angell, M.; House, J.; Jones Bock, S. (2007)* 4. Parsons, S.; Lewis, A.; Ellins, J. (2009). The views and experiences of parents of children with autistic spectrum disorder about educational provision: Comparisons with parents of children with other disabilities from an online survey 5. Forest, E.; Horner, R.; Lewis-Palmer, T.; Todd, A. (2004). Transitions for young children with autism from preschool to kindergarten 6. Quintero, N.; McIntyre, L. (2011). Kindergarten transition preparation: A comparison of teacher and parent practices for children with autism and other developmental disabilities
Search term 6	"Parents experiences of transitions and children with autism"
Relevant topics N = 4*	Stoner, J.; Angell, M.; House, J.; Jones Bock, S. (2007)* Forest, E.; Horner, R.; Lewis-Palmer, T.; Todd, A. (2004)* Stoner, J.; Jones Bock, S.; Thompson, J. (2005)* Parsons, S.; Lewis, A.; Ellins, J. (2009)*
Search term 7	"Parents experiences and children with autism starting school"
Relevant topics N = 0	
Search term 8	"Parents experiences and children with ASD starting school"
Relevant topics N = 0	
Inclusion criteria:	<i>As previously</i>
Exclusion criteria:	<i>As previously</i>
Suitable references for review: N = 2	1. Stoner, J.; Angell, M.; House, J.; Jones Bock, S. (2007) 2. Quintero, N.; McIntyre, L. (2011)

Appendix 2

Quality in mixed method studies

Date of research:				
Author(s):				
Title:				
Relevance to current research	Topic /Theory /Participant group / Domain (health/education)			
Research publication	Book /Book chapter /Journal article / Other			
Research aims				Clearly stated?
Research type (a)	Experiment / Survey / Literature review / Intervention			
Methodology	Appropriate to study	Random sample	Relevant population	Repeatable
Design	No control	Cohort (two group pre and post)	Before and after study (one group)	Case control
Research type (b)	Analysis/ exploration / Survey / Literature review / Intervention			
Methodology	Appropriate to study	IPA	Grounded theory	other
Data collection	Methods clearly described	Appropriate	Systematic	Validity
Literature review	Discussion of previous literature / Link to previous literature			
Outcomes				
Quality	Rigour	Relevance	Suitability for inclusion	Role of researcher
Summary of main findings				

Quality in quantitative studies

Date of research:				
Author(s):				
Title:				
Relevance to current research	Topic /Theory /Participant group / Domain (health/education)			
Research publication	Book /Book chapter /Journal article / Other			
Research type	Experiment /Survey / Literature review / Intervention			
Research aims				Clearly stated?
Methodology	Appropriate to study?	Random sample?	Relevant population?	Repeatable?
Design	No control	Cohort (two group pre and post)	Before and after study (one group)	Case control
Literature review	Discussion of previous literature / Link to previous literature			
Outcomes				
Quality	Rigour	Relevance	Suitability for inclusion	Validity
Summary of main findings				

Quality review of research studies in the literature review

Quality in quantitative studies

Date of research: 2009				
Author(s): Parsons, S., Lewis, A., Ellins, J.				
Title: The views and experiences of parents of children with autistic spectrum disorder about educational provision: Comparisons with parents of children with other disabilities from an online survey				
Relevance to current research	Topic /Theory /Participant group / Domain (health/education)			
Research publication	Book /Book chapter / Journal article / Other			
Research type	Experiment / Survey / Literature review / Intervention			
Research aims	To compare the views of parents of children with ASD and parents of children with other disabilities about educational provision across mainstream and special schools			Clearly stated? Yes
Methodology	Appropriate to study? Yes	Random sample? No	Relevant population? Yes	Repeatable? Yes
Design	No control Comparison study, no control	Cohort (two group pre and post) No	Before and after study (one group) No	Case control No
Literature review	Discussion of previous literature / Link to previous literature Links made to previous literature and legislation.			
Outcomes	Survey revealed similarities and differences between parents views			
Quality	Rigour Interviews would have enhanced information; sample not representative; limitations discussed	Relevance Some relevance - parents experiences not explored; information re: concerns of parents in ed prov.	Suitability for inclusion With caveat re: relevance to particular subject matter	Validity Exploratory in nature – not making claims
Summary of main findings	majority of parents in both groups were satisfied with their child's current educational provision; the children attended their school of choice and most were neutral or positive in relation to how the schools had accommodated their children; parents of children with ASD more likely to say their children had additional support needs; were more			

	likely to have concerns that school staff would have knowledge of their child's condition. Parents of both groups agreed that their children would have difficulties getting a job but disagreed that they would have difficulties continuing in education in the future. In relation to vertical transitions, both groups indicated concerns.
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Quality in quantitative studies

Date of research: 2004				
Author(s): Forest, E.J.; Horner, R.H.; Lewis-Palmer, T.; Todd, A.W.				
Title: Transitions for young children with autism from preschool to kindergarten				
Relevance to current research	Topic /Theory /Participant group / Domain (health/education) Provides background to transitions for children with ASD to more formal schooling			
Research publication	Book /Book chapter / Journal article / Other			
Research type	Experiment / Survey / Literature review / Intervention			
Research aims	3 aims: to identify / integrate elements in trans process from literature; to develop a tool to assess transition process; to field test tool with 3 families			Clearly stated? Yes
Methodology	Appropriate to study? Yes but small sample	Random sample? No	Relevant population? Yes	Repeatable? Some description of methods – not detailed
Design	No control No	Cohort (two group pre and post)	Before and after study (one group)	Case control
Literature review	Discussion of previous literature / Link to previous literature Some background provided and linked to previous literature			
Outcomes	Instrument developed to assess transitions for children with ASD; confirmation of what literature says about importance of certain elements in trans process; data not provided linking transition elements with transition success.			
Quality	Rigour Small non-random sample; no link made to trans outcomes.	Relevance With caveat – partial relevance.	Suitability for inclusion With caveat	Validity No claim to validity; literature confirmed.
Summary of main findings	Exploratory study; results suggest follow up development and testing of transition tool would be useful in supporting design of transition programmes for children in cohort.			

Quality in quantitative studies

Date of research: 2011				
Author(s): Quintero, N.; McIntyre, L.				
Title: Kindergarten transition preparation: A comparison of teacher and parent practices for children with autism and other developmental disabilities				
Relevance to current research	Topic /Theory / Participant group / Domain (health/education)			
Research publication	Book /Book chapter / Journal article / Other			
Research type	Experiment / Survey / Literature review / Intervention			
Research aims	To investigate teacher concerns regarding the transition to kindergarten; to investigate teacher and parent-reported transition preparation practices for children with ASD and children with developmental disabilities			Clearly stated? Yes
Methodology	Appropriate to study? Yes	Random sample? No	Relevant population? Yes	Repeatable? Yes
Design	No control Comparison study, no control	Cohort (two group pre and post) No	Before and after study (one group) Partial	Case control
Literature review	Discussion of previous literature / Link to previous literature Links made to previous literature, gaps in literature identified.			
Outcomes	Preliminary findings regarding transition experiences and practices for teachers and parents of children with ASD and DD.			
Quality	Rigour Interviews would have enhanced information; cross-informant data used.	Relevance Some relevance but not enough to include in study- parents experiences not explored	Suitability for inclusion With caveat re: relevance and rigour	Validity Exploratory in nature – not making claims
Summary of main findings	Trans practice not individualised; endorsed practices such as monthly meetings, contact with parents. Transition meeting with preschool staff, written communication with parents; barriers to effective trans. – lack of time and lack of links with preschool staff.			

Quality in qualitative studies

Date of research: 2005				
Author(s): Russell, F.				
Title: Starting school: The importance of parents' expectations				
Relevance to current research	Topic / Theory / Participant group / Domain (health/education)			
Research publication	Book / Book chapter / Journal article / Other			
Research type	Analysis/ exploration	Survey	Literature review	Intervention
Research aims	To explore the content, origins and development of parents' expectations when their disabled child moved into school and the extent to which parents perceived that these were realised after the first year in school.			Clearly stated? Yes
Methodology	Appropriate to study? Yes	IPA	Grounded theory	other emancipatory research
Data collection	Methods clearly described Yes; reference to epistemology and theory and method described	Appropriate to research question Yes	Systematic Yes	Validity Yes
Literature review	Discussion of previous literature Yes	Link to previous literature Links to literature on parents' needs, expectations, policy, theory		
Outcomes				
Quality	Rigour Difficult to assess – not enough info about method and theoretical links	Relevance Yes	Suitability for inclusion With caveat re: rigour	Role of researcher Described but not in detail, no ref. to epistemology, reflexivity.
Summary of main findings	Individual and shared expectations of child, support profs and local SEN systems - including the child would make progress at school; commitment and expertise of staff;			

Quality in qualitative studies

Date of research: 2007				
Author(s): Stoner, JB; Angell, ME; House, JJ; Jones Bock, S.				
Title: Transitions: Perspectives from parents of young children with ASD				
Relevance to current research	Topic / Theory / Participant group / Domain (health/education)			
Research publication	Book / Book chapter / Journal article / Other			
Research type	Analysis/exploratory	Survey	Literature review	Intervention
Research aims	To investigate the perspectives and concerns of parents of young children with ASD related to transitions			Clearly stated? Yes
Methodology	Appropriate to study? Yes but not clearly stated; no ref. to epistemology	IPA	Grounded theory Based on grounded theory	Other Collective case study: Interview, observation, documentation
Data collection	Methods clearly described Small sample, purposively selected; data analysis described	Appropriate to research question Yes	Systematic Triangulation described; grounded theory-type; confirmability	Validity? Sample less homogeneous than desirable.
Literature review	Discussion of previous literature Yes	Link to previous literature Yes and discussion of links to previous literature		
Outcomes	Six major themes to inform knowledge about perspectives of parents; recommendations for successful transitions offered; horizontal versus vertical transitions discussed.			
Quality	Rigour Triangulation, member checking, cross checking described	Relevance Children were aged 6-8 so older than in this study	Suitability for inclusion Caveat: parents of older children; 2 post-trans.	Role of researcher Described but no mention of reflexivity
Summary of main findings	Effective transitions are child-centred; communication between home and school vital; need for understanding the child; barriers to successful transitions identified; parental focus is on horizontal transitions; parents identified effective transition strategies – 3-step strategy.			

Quality in qualitative studies

Date of research: 2012				
Author(s): Rozanna Lilley				
Title: It's an absolute nightmare: Maternal experiences of enrolling children diagnosed with autism in primary school in Sydney, Australia				
Relevance to current research	Topic / Theory / Participant group / Domain (health/education)			
Research publication	Book / Book chapter / Journal article / Other			
Research type	Analysis /exploration	Survey	Literature review	Intervention
Research aims	Analysis of maternal narratives of informal school exclusion at the point of transition into primary school in Sydney.			Clearly stated? Yes
Methodology	Appropriate to study? Yes	IPA	Grounded theory	other Narrative analysis
Data collection	Methods clearly described No; no ref to epistemology	Appropriate to research question Yes	Systematic Method not described adequately	Validity? Not able to determine exactly
Literature review	Discussion of previous literature Yes	Link to previous literature Links to literature on stigma, exclusion, disability studies		
Outcomes	Revealing and exploring of stigmatisation of this group provides insight into pervasive blocks and barriers to inclusive education for children with ASD and parents.			
Quality	Rigour Difficult to assess – not enough info about method and theoretical links	Relevance Yes	Suitability for inclusion With caveat re: rigour	Role of researcher Described but not in detail, no ref. to epistemology, reflexivity.
Summary of main findings	Claims made about the experiences of mothers of children with ASD starting school – 10 of 22 reported explicit stigmatising practices; evidence of broad systemic tolerance in the region for students perceived to be different and potentially disruptive.			

Quality in qualitative studies

Date of research: 2014				
Author(s): Rozanna Lilley				
Title: Professional guidance: maternal negotiation of primary school placement for children diagnosed with autism				
Relevance to current research	Topic / Theory / Participant group / Domain (health/education)			
Research publication	Book / Book chapter / Journal article / Other			
Research type	Analysis/ exploration	Survey	Literature review	Intervention
Research aims	Exploration of how different forms of professional guidance impact on maternal negotiation of finding an appropriate school placement for their child with ASD			Clearly stated? Yes
Methodology	Appropriate to study? Yes; but no epistemology; reflexivity	IPA	Grounded theory	Other Narrative analysis
Data collection	Methods clearly described No	Appropriate to research question Yes	Systematic Method not described adequately	Validity? Not able to determine
Literature review	Discussion of previous literature Yes	Link to previous literature Some links to own research and literature but not clearly linked in conclusion		
Outcomes	Claims made about the experiences of mothers of children with ASD starting school in their attempts to find the best place for their child; experiences limited to negotiations and interactions with professionals in Australia; some of the claims resonated with this researcher's experience in practice and in what participants in this study experienced.			
Quality	Rigour Difficult to assess – not enough info about method and theoretical links	Relevance Yes	Suitability for inclusion With caveat re: rigour	Role of researcher Described but not in detail, no ref. to epistemology, reflexivity.
Summary of main findings	In analysing child's transition, agency of mothers need to be acknowledged; relations between professional and powers discussed in terms of power differentials; ASD matrix and democratisation of ASD – professionals now equally offer information but this can be conflicting and confusing.			

Quality in mixed method studies

Date of research: 2012				
Author(s): Miles, K. G.				
Title: An exploration of the transition from nursery to primary school for children with autism spectrum conditions (ASC): Parents' perspectives				
Relevance to current research	Topic /Theory /Participant group / Domain (health/education)			
Research publication	Book /Book chapter /Journal article / Other Doctoral thesis			
Research aims	To explore parents' experiences and views of the transition process from nursery to primary school for their child with ASC; to inform future transition support for parents and children in the borough			Clearly stated? Yes
Research type (a)	Experiment / Survey / Literature review / Intervention			
Methodology	Appropriate to study Yes	Random sample N/a	Relevant population Yes	Repeatable N/a
Design	No control N/a	Cohort (two group pre and post)	Before and after study (one group)	Case control
Research type (b)	Analysis/ exploration / Survey / Literature review / Intervention			
Methodology	Appropriate to study Yes	IPA Yes	Grounded theory	other
Data collection	Methods clearly described Yes	Appropriate Yes	Systematic	Validity Small sample
Literature review	Discussion of previous literature / Link to previous literature Yes			
Outcomes	Proposed to inform practice in LA			
Quality	Rigour questions re use of IPA: little demonstration of hermeneutic or interpretation; triangulation: mixed methods; questionnaire use.	Relevance Partial – children had already started school	Suitability for inclusion Yes with caveat – not peer reviewed	Role of researcher Reference made to reflexivity but role in interpretation not clearly described
Summary of main findings	Relationships with professionals (communication, trust, support, seeking expertise), Being the parent of a child with ASC, Importance of early identification.			

Quality in mixed method studies

Date of research: 2004				
Author(s): Fox, S.; Farrell, P., & Davis, P.				
Title: Factors associated with the effective inclusion of primary-aged pupils with Down's Syndrome				
Relevance to current research	Topic /Theory /Participant group / Domain (health/education)			
Research publication	Book /Book chapter / Journal article / Other			
Research aims	To undertake a detailed study of a relatively small number of school to learn more about how support pupils with DS is managed and quality of teamwork; to look at how attitudes of staff, parents and pupils affected inclusion and management of support in schools.			Clearly stated? Yes
Research type (b)	Analysis/ exploration / Survey / Literature review / Intervention Case studies			
Methodology	Appropriate to study Yes	IPA	Grounded theory	other Interview Observation Focus groups
Data collection	Methods clearly described Yes	Appropriate Yes	Systematic Yes	Validity As per mixed methods study
Literature review	Discussion of previous literature / Link to previous literature Yes			
Research type (a)	Experiment / Survey / Literature review / Intervention Sociometric assessment			
Methodology	Appropriate to study Yes	Random sample n/a	Relevant population	Repeatable N/A as part of case study
Design	No control N/A	Cohort (two group pre and post)	Before and after study (one group)	Case control
Outcomes	Factors identified which influence inclusion of children with DS in mainstream. Parents views solicited.			
Quality	Rigour Comprehensive approach to data collection Triangulation of	Relevance	Suitability for inclusion To compare experiences of with	Role of researcher Not outlined

	methods		another population	
Summary of main findings	<p>Most parents referred to a struggle in finding mainstream provision for their children. Parents interviewed felt that TAs were crucial to the child's effective inclusion. Some parents in the study expressed concern at the poor liaison between school staff and themselves. A small minority reported feeling unable to discuss concerns with staff. The study identified the following features of the school that promoted successful inclusion: the centrality of the teacher in the process of including the child, complementary relationships between support staff and the class teacher, the capacity of the class curriculum to include the child, and the quality of communication between teacher and pupil, teacher and TA, teacher and advisory teacher, and teacher and parents/carers.</p>			

Appendix 4

Imaginary letter to participants explaining my intentions around interpretation

2nd May 2014

Dear Participant,

I would like to thank you for taking part in my research and for allowing me to record and write out the story of your experiences. In this study I will interpret what you said to give an account of what I think you meant. This is my interpretation of what you meant. I have put my meaning on your meaning and I don't claim that it is the right meaning. Yours is the truest account and only you can know what you really meant. I offer only one interpretation among many.

I really hope I have done your account justice and that I have captured the essence of your intentions.

Yours sincerely,

Micaela Connolly

Ethical approval from University of East London Ethics Board

ETHICAL PRACTICE CHECKLIST (Professional Doctorates)
--

SUPERVISOR: Sharon Cahill **ASSESSOR:** James Walsh

STUDENT: Micaela Connolly **DATE (sent to assessor):**
07/12/2012

Proposed research topic: Experiences of parents whose children with autism spectrum disorder are starting primary school.

Course: Professional Doctorate in Applied Educational and Child Psychology

- | | |
|--|-----|
| 1. Will free and informed consent of participants be obtained? | YES |
| 2. If there is any deception is it justified? | N/A |
| 3. Will information obtained remain confidential? | YES |
| 4. Will participants be made aware of their right to withdraw at any time? | YES |
| 5. Will participants be adequately debriefed? | YES |
| 6. If this study involves observation does it respect participants' privacy? | NA |
| 7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically? | NA |
| 8. Is procedure that might cause distress to participants ethical? | YES |
| 9. If there are inducements to take part in the project is this ethical? | NA |

10. If there are any other ethical issues involved, are they a problem? NA

APPROVED

YES		
-----	--	--

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: JW Date: 3/1/2013

RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)

SUPERVISOR: Sharon Cahill **ASSESSOR:** James Walsh

STUDENT: Micaela Connolly **DATE (sent to assessor):**
07/12/2012

Proposed research topic: Experiences of parents whose children with autism spectrum disorder are starting primary school.

Course: Professional Doctorate in Applied Educational and Child Psychology

Would the proposed project expose the researcher to any of the following kinds of hazard?

1 Emotional NO

2. Physical NO

3. Other NO
(e.g. health & safety issues)

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as: HIGH / MED / LOW

APPROVED

YES	
-----	--

MINOR CONDITIONS:

REASONS FOR NON APPROVAL:

Assessor initials: **JW** Date: 3/1/2013

For the attention of the assessor: Please return the completed checklists by e-mail to ethics.applications@uel.ac.uk within 1 week.

SCHOOL OF PSYCHOLOGY

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.

UEL
University of
East London
www.uel.ac.uk

School of Psychology Professional Doctorate Programmes

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,



Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937
e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology



The University of East London has campuses at London Docklands and Stratford
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



12th March 2013

**RE: Research into experiences of parents whose children with autism
spectrum disorder are starting primary school**

Dear Parent,

My name is Micaela Connolly and I am a psychologist working with the Autism Services (South Lee) in Cork. The service operates under the Brothers of Charity Southern Services. I work with young children with autism and their families and I am carrying out a research study into the **experiences of parents whose children with autism spectrum disorder are starting primary school**. I hope to conduct individual interviews with parents to get a sense of their personal experience of this situation. These interviews will be informal and confidential and should take about an hour to an hour and a half. To capture all the information, interviews will be audio-recorded and the data will be transcribed and analysed to find out more about parents' experiences and feelings. I hope that information from the interviews will be used to help professionals to better understand the needs of parents and children at this time. The research paper is in part completion of a doctoral course I am undertaking at the University of East London.

If you are interested in taking part in an individual interview with me, could you read the information attached and send me the *Consent to be Contacted* slip in the stamped, addressed envelope. I will then make contact with you to discuss more about what would be involved and, if you're happy to do so, we can set up a time to meet.

You are not in any way obliged to take part in this study, and people who do take part are free to withdraw at any time, during the interview or afterwards up to the compilation of the research into a report. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any need to give a reason.

Please feel free to contact me if you have any questions regarding this study. I look forward to hearing from you.

Yours sincerely,

Micaela Connolly
Senior Educational Psychologist,
Autism Services, (South Lee)

Appendix 7

Consent to be Contacted

by the researcher of this study:

Experiences of Parents whose Children with Autism Spectrum Disorder are
Starting Primary School

I would be interested in hearing more about this study.

I give my permission for you to contact me to talk about what it would mean for me to take part in this study.

A good time to ring would be _____

My name is: _____

My contact number is: _____

My contact e-mail is: _____

I confirm that my child will be starting mainstream primary school in Sept 13

Signed: _____

Date: _____

Appendix 8

Experiences of parents whose children with autism spectrum disorder are starting primary school

Information Sheet for Participants

Introduction

The purpose of this piece of research is to find out about the experiences of parents whose children with autism spectrum disorder (ASD) are starting primary school in September 2013. Please take some time to read this information sheet so you know who I am, what the research is about, and what it involves for people who decide to take part.

The researcher

My name is Micaela Connolly and I work as an educational psychologist with the Autism Services (South Lee). This service operates under the Brothers of Charity Southern Services I am conducting this research as part of a doctorate in Applied Educational and Child Psychology that I am undertaking at the University of East London (UEL). I will be supervised by Professor Irvine Gersch, Programme Director on the Doctoral Programme at UEL, and Dr Sharon Cahill, senior lecturer at UEL. I have received ethical approval to undertake the study from the Brothers of Charity Southern Services through their ethics committee and from the UEL through their ethics board.

The research

I am carrying out this research because I want to find out about parents' experiences in this situation from parents themselves. I'd like to find out what parents feel about their children starting school, about what educational options they have, what hopes they have, what concerns they have, etc. I hope the information gained will help improve understanding of what it is like for parents at this time.

What's involved in taking part?

If you are interested in taking part in this study, you can send me the Consent to be Contacted slip in the envelope provided and/or contact me at:

Micaela Connolly
Autism Services (South Lee)
Marian House,
Leghenamore,
Togher,
Cork
Telephone: 021-4347087
e.mail: micaela.connolly@bocss.org

We can arrange a meeting which will take place at the Autism Services <Town> office at a time that suits you. We can discuss any questions you have at this meeting.

I will ask you to sign a consent form and then I will carry out an interview with you which will last about one to one and a half hours. The interview will be taped so that I can listen to it afterwards and transcribe it. I will either transcribe the information myself or I will ask a trusted third party to do so in confidentiality. I will use these transcriptions to help me understand the issues and experiences that parents in your particular situation have. The questions I will ask will involve finding out what it's like to be a parent of a child with ASD at this time, what concerns you have, what hopes and goals you have, how you feel about your child's educational options.

Am I obliged to take part?

You do not have to take part in this research project and, if you agree to take part, you can withdraw at any time without giving any reason. You can withdraw during the interview or afterwards. Should you choose to withdraw from the study you may do so without disadvantage to yourself and this will not in any way affect the quality of the service you receive from the Autism Services.

After the interview you will have an opportunity to ask any questions and discuss any concerns you have.

What will happen to my information if I agree to take part?

Your information will be taped as mentioned and then transcribed. All data will be stored in secure and confidential files by me. The names of people taking part will be coded to protect anonymity. This code will be kept in a secure and confidential database. Only I will have access to this database.

You have the right to withdraw your responses at any time without giving a reason up to the time the data is compiled into a report and/ or published. If you decide you want to withdraw from the study please let me know by contacting me at the numbers or e-mail address above. If you have completed the interview I will ask what you would like to happen to the data. It can either be included in the study, or destroyed. Either option is perfectly acceptable, prior to compilation / publication. After the report has been submitted or published it is not possible to remove or omit references to an individual person's responses.

If the research is published the anonymised processed data will be kept securely for a maximum of 5 years from date of publication. Then hard copies will be shredded and electronic copy destroyed under my supervision. As part of the doctoral programme, I will write up a report of the research. To illustrate the themes I will be exploring I may include anonymous extracts from interviews with parents. These extracts will not include any information that could identify individual participants.

I hope to write a short article for publication in an academic journal, which may also include brief anonymous extracts of the interview with you. I may also present findings to colleagues and at conferences in the future.

What are the possible disadvantages and risks of taking part?

I am aware that we may be discussing important and potentially distressing issues and situations and I intend to put your comfort first. I will take every measure to minimise the risk of distress. You do not have to answer questions

that you don't want to. You can stop the interview at any time. If you become uncomfortable or upset, the interview can be stopped or concluded. I am bound to comply with ethical standards for researchers as outlined by the Brothers of Charity Southern Services, UEL and the Psychological Society of Ireland. I have also consulted with guidelines from the British Psychological Society.

It is very important to me that you are treated fairly, with dignity and respect, and that your rights to confidentiality are upheld.

When the interview is finished, I will be available to talk about any issues or concerns that were raised during it. An information sheet will be available with details of colleagues who could provide further support.

If you have a concern about any aspect of this study, you can contact me and I will do my best discuss your concerns. If you have any queries regarding the conduct of the research in which you are being asked to participate, please contact the Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ. Tel: 020 8223 4493. Email: m.finn@uel.ac.uk

Consent to Participate in a Research Study

Experiences of Parents whose Children with Autism Spectrum Disorder are
Starting Primary School

I have read the information leaflet relating to the above programme of research in which I have been asked to participate and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to the data. It has been explained to me what will happen once the study has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me.

Having given this consent I understand that I have the right to withdraw from the programme at any time, during the interview, or afterwards, without disadvantage to myself and without being obliged to give any reason.

I understand that I have the right to withdraw my responses at any time before the information is compiled into a report.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

Date:

Debriefing Information Sheet

Thank you very much for taking part and making this study possible.

This study aimed to explore the experiences of parents of children with ASD who are starting primary school. I was interested in finding out what it's like to be a parent in this situation.

The literature and research that has been conducted on children starting primary school shows that it can be an anxious time for many parents. This is especially true for parents of children with ASD as times of change and transition can be particularly difficult for their children. When I thought about carrying out this study, I looked to see what research had been done into what parents of children with ASD feel about their children starting school and I didn't find much on parent's experiences and perspectives. I felt it would be very useful for parents and professionals working with children with ASD to know more about what parents think and feel.

Sources of comfort and help

Talking about your experiences may have left you feeling low or upset. If you feel you need support and comfort, there may be a number of sources you could access. The most immediate sources of comfort and help are likely to be your own family and friends.

My colleagues in the service are aware that some parents in the service are taking part and have offered to be available to support parents around any issues that arise from this interview. You have the option of talking to them about how you feel.

Contact details: Autism Services, address, telephone number.

The <Counselling Service> is located in <town> and provides a reduced cost counselling service with qualified counsellors.

Contact details: Tel: xxx-xxxxxx

Email: xxxxx@xxxx.xxx

I will be available after the interview to discuss any issues that came up and we can talk about possible supports if necessary. You are welcome to contact me afterwards if you would like to discuss any issues or concerns arising from the interview.

Contact details: Micaela Connolly, Address, Cork;

Tel: 021-xxxxxxx, 087-xxxxxxx; e-mail: micaela.connolly@bocss.org

Interview Schedule

I'd like to hear about your experiences, as a parent of a small child with ASD.
I'm interested your experiences and feelings about your child starting school.

1. Can you tell me something about your little one with ASD?
What kind of things does he like to do?
Is he in preschool?
How is he getting on there?
2. Have you chosen a primary school for him?
What was choosing a place like?
What kind of place is it?
Will he be getting supports in school when he starts?
3. What things are important for you around his education?
What would you like him to get out of school?
4. What do you think he feels about starting school?
5. What are your feelings about him starting school?
6. Do you feel the experience is different for parents of children who have ASD and parents of children who don't?
7. What advice would you give to other parents in this situation?
8. What would you like the teachers and others involved to know?
9. Have I missed anything important?

epistemology - finally April 13 -
it's critical realist which suits IPA
because I'm assuming people have
these experiences and I can access
them.

30 April

Have organised pilot for next
week. Need to send new schedule
to Sharon & Dine.
Wale & Brinkman - choosing
as good into in this book -
detailed phenomenology -
"mimesis"

1 participant identified in book
who is interested - need to see
how many more I can get & My
Verity.

No full exclusion criteria - for
the group I want to sample,
none are newly diagnosed,
for instance.

Gave them the chance to say no if
they wish."

3rd May

To get a sense of how to phrase
questions and how interview
might go, I typed out an
imaginary interview with myself
as participant - only realising
now that I am in the position of
having a child transitioning to
school in Sept 13!

Found that I referred a lot to
his other brother and previous
experience. My previous experience
of my own school was in these -
some learning about my own
feelings!

Need to look at my own assumptions
can they be bracketed?

- that people have feelings -
the phenomena under
investigation
- that these feelings/experiences
can be discovered in an
interview
objectivity is limited

- that I'll be able to discover people's feelings / experiences;
 - critical realist perspective;
 - that I know enough about the subject area;
 - that this will be a useful exercise and will inform research;
 - that there will be hope, worry, stress, anxiety, concern about placements and supports, that it won't be easy.
- * → need to ask → what would be helpful? what would you like to happen?

After grapple with Thérèse - there is a social constructionist component to some studies... Why are you critical realist?

* Need to compare studies from the differing epistemologies.

Q What are your feelings about being starting school? How do you imagine his future in school?

Thoughts on RIT Interview

- This is much harder than I thought
- developing the interview - felt a bit fake at the start;
- trying not to reassure / say too much
- trying to stay out of therapeutic mode
- trying to elicit experiences without getting too deep (therapeutic interview)
- trying to be neutral
- just trying to elicit experiences! Or did I just get a descriptive / narrative interview - what were the experiences?
- Got some insight into events, episodes, feelings, thoughts
- Extra q - is it different? to others?
- Probs with equipment - camera ran out in way too much.

concern that interview only lasted 40 mins - did it yield enough?

- Need debriefing sheet

- camera + phone

- interview schedule

Started transcription

conscious of difference between what I hear and what's actually said though I think I got the gist. Involving to look @ the transcription and see what's different between listening + reading / interpreting text.

→ remember looking for meaning the sense people make of the phenomena. "I was terrified" when she says I was terrified - need to follow up - can you tell me more about that?

Interview 1

Seemed to show 35 mins; did not want to probe too much. This woman has a lot on and v. negative experiences with schools. Despite this she has made the best of the situation and has worked very hard to develop a relationship with school whereby she understands the children's needs. She may have been a bit upset around feelings such as anger and I feel I got a bit of info from her - not wanting to delve too deeply; felt this would have been disrespectful and invasive.

She has a children on spectrum and this is second time starting her son. Thailed question from schedule to Sharon and Deane. Sharon got back to say questions looked okay but need to send transcript over so they can see what's going on. Started transcription - trying to be faithful. Kvale talked about

validity/reliability - so being faithful in some way in transcribing is an attempt. Some info - a lot, lost - tone/emphasis/non-verbal info / pauses - but this is IPA, so it's about the text - exegesis in a way. Saw how much I can mishear, needed to over and over again to get phrasing / vocab exactly right. Small mistakes but could impact later. Surprised by 1 piece that I thought we'd discussed afterwards without the sound recording - personal about "breakdown": V. personal but V. honest.

Some of my questions were leading and just got affirmation. Hard to press some points.

Transcribing and Coding Paul's mum's transcript - transcript 1
Transcribed verbatim and I went over it again to check wording, emphasis and pauses. Sent to Drive and Sharon to check. Dandelion ^{was} out
Read through it and, per Smith, etc., looked at descriptive, linguistic, initial codes and conceptual features

Looked for experiences and thoughts and feelings to make sense I had captured them - orange highlighter for feelings, green for thoughts, ④ looked at codes, referred to text, recorded themes on left (purple).

⑤ as I was doing this I started to think about importance of some themes - clustering -> yellow highlighter and referred back to text.

⑥ linguistic sometimes went from I to you - blue highlighter

⑦ some interpretation seemed to be happening as I read and re-read - sudden thoughts like "oh this is like where he's fighting the system - so is she" or conflict or freedom & conformity - struggle - coded pile contradictions

Then I reread Smith et al. to see what I could do next - start focusing on themes and make a table of themes and overarching themes with examples of text and line nos.

④ Re-read codes and possible themes - moving away from text and began to elaborate themes.

⑤ I also wrote down an overall summary of what I felt might be going on for Paul's mum.

Interview 2

1/06/13

Travelled 1 1/2 hrs, got a little lost. Mum's sis and youngest were in kitchen also for a time. Initially, I thought it wouldn't work but they were so quiet and preoccupied for 2 interruptions. Dad came in and I had to move car. More able to ask as and follow up than I felt last time. Team had impression that life can be v. v. difficult, interesting comments and perspectives. 2 children with ASD and concerns re: younger "David" who is starting out of turns but has camp to special class so that's a problem from my sampling point of view - do I include + change the study? I looked for mainstream children but this has changed for David since he got a place in the unit. I feel her experience is relevant - she has an older child in mainstream and a younger child going to S.C.

Appendix 13

Sample transcript (Transcript 5 – Hannah)

	1	So, that's on there (indistinct) ah, do you
	2	want to tell me about James, just to start?
	3	I forgot to ask you, is it just about, kind of,
	4	how he ..?
	5	I suppose it's about .. what it was like ..
	6	am .. choosing school .. you know,
	7	thinking about him going to primary school
	8	..
	9	Well, initially, when he wh- when he was
	10	maybe about .. just turned three when we
	11	found out (yeah) so luckily, my – I have a
	12	neighbour who has a son on the spectrum
	13	(yeah) she told me about the preschool
	14	(yeah) in <town> (yeah) and actually there
	15	was nothing else around (yeah) so had I
	16	not known about that I would never have ..
	17	(yeah) known to put him there and he got
	18	a year there and (yeah) then we had to
	19	fight to get the second year and (right) and
	20	that gave me two years then to decide
	21	where to put him and at that stage we
	22	knew he was well able for .. (yeah)
	23	mainstream (yeah) and it was just a
	24	matter of finding the right school and
	25	again (yeah) I wanted something kind of
	26	small (yes) that .. am .. because my older
	27	son had gone to a bigger school (yes) and
	28	I just didn't want that for him; he wouldn't
	29	have been able (yeah) so we chose our
	30	local school here; it's only a hundred and
	31	forty children so .. (brilliant) and his older
	32	sister goes there as well ..(right) .. yeah

	33	(great)
	34	So, what's he like? What kind of a little
	35	guy is he; what does he like to do?
	36	.. Am, he - he's big into computers (yeah?
	37	great) Since, actually since he started
	38	school, he's really kind of come out of
	39	himself and he likes going out playing with
	40	the (brilliant, yeah) yeah he likes to go
	41	play with our neighbours and we've all
	42	grown up together (yeah) so close around
	43	here (yeah yeah) so he likes .. and he has
	44	an older brother and sister so he likes to
	45	copy what they do like so (yeah) hence it's
	46	it's three skateboards and three
	47	bikes,(yeah) and he (he's doing what
	48	everyone else is doing) he likes, yeah.
	49	He's doing his version, I mean he can't
	50	cycle yet but he likes (yeah) to potter
	51	along beside them (yes), you know. He
	52	likes to be .. part of .. (yeah) everything
	53	(yeah).
	54	So it sounds like it was kind of .. not .. or
	55	what was it like, do you know, thinking
	56	about the primary school, thinking about ..
	57	it sounds like you didn't have any doubts
	58	that he'd be able ..
	59	After two years .. after the second year
	60	(yeah yeah) I knew then he'd be able
	61	(yeah yeah). There is a unit in the school
	62	here but .. they had told me that he
	63	wouldn't be suitable for that because the
	64	kids going there were more .. am .. (yeah)
	65	what's the word again? .. am ... you know
	66	higher .. (yeah) .. oh, I can't think of the

	67	word, sorry now ..
	68	They .. had more difficulties?
	69	What? They were lower functioning so
	70	they had more (indistinct) in school (yes)
	71	and he kind of mimics as well so he's
	72	(yeah) so it was a matter of finding the
	73	right school.
	74	Yeah.
	75	And I switched schools for my <middle
	76	child> ... had to be a year in school before
	77	he started (yeah) so I knew (yes).. and
	78	they were so accommodating.
	79	Yeah. Did you switch because of James?
	80	Because of my older son (okay right).
	81	He'd gone through the school - I knew it
	82	wasn't -great (okay). We found out you
	83	see, around the same time he has
	84	Asperger's (Okay okay). He's – he's
	85	thirteen now (okay). So this was maybe
	86	three years ago when we found out (right).
	87	Yeah .. and I knew there - there was a
	88	couple of things – around <i>him</i> that (yeah)
	89	the school weren't a bit helpful (yeah) - the
	90	last school (okay) and it was very big as
	91	well (yeah). So, you're just – you're just a
	92	number.
	93	So he's gone out of that school? your
	94	older son is in secondary
	95	So we let him finish out because (yeah
	96	yeah) this was fifth – sixth class? So he
	97	finished out (yeah) and then .. I know, I
	98	was looking for a new school (yeah) for
	99	Con anyway so I switched my older girl
	100	(yeah) – she's <number> years older than

	101	James (yeah) into <number> class (yes)
	102	in the new school and then I <i>knew</i> it was
	103	the right school for him (yeah yeah, that's
	104	brilliant) yeah (that was good). And
	105	anyone who'd know – who knew the
	106	school then (yeah) – said they were very –
	107	very obliging (yeah).
	108	And what were you looking for, like, what
	109	did you think would be right for him?
	110	Am, I wanted somewhere that would kind
	111	of give him an arm around the shoulder
	112	(yes) without .. making him stand out from
	113	everyone else (yeah yeah) and that's what
	114	he's got; he's just got a little bit of extra
	115	guidance, like he - they wouldn't give him
	116	an sna (special needs assistant) because
	117	he doesn't have any extra needs .. that's
	118	eh the term they use now (half
	119	laugh)(okay). Am, I kind of would have
	120	liked one, but at the same time I said I'm
	121	glad (yeah) he – he was - they think he's -
	122	doesn't need one (yeah) if you know what
	123	I mean (yeah yeah). Ah, so the teacher
	124	just – bit – eh, I suppose to keep a little
	125	extra eye on him and he gets resource
	126	(yeah). He goes out for an hour a day I
	127	think maybe (yeah yeah). They're kind of
	128	phasing it in (yeah) to see what he needs
	129	but I don't think .. like he's great
	130	academically. He looks something and
	131	knows it (yeah). He's great that way
	132	(yeah) it's just the social and..(yes) So I
	133	think this is perfect for him (yeah) you
	134	know the small school, it's just what he

	135	needs (yeah yeah, so yeah, gosh). You
	136	can even see in everything – he’s just so
	137	confident now (yeah) since he’s starting
	138	and he’s talking with his friends and ..
	139	yeah.
	140	What’s that like?
	141	It’s fantastic, you know and he’s ..
	142	especially with his family now (yes) and
	143	he’s talking about his friends and his
	144	girlfriends (laughs) (yeah!)
	145	Oh right, so he’s well on the way (laughs)
	146	Yeah, (indistinct) he’s settled in (that’s
	147	great).
	148	Am, in terms of school, what – what were
	149	they like to deal with – the people in
	150	school? You know ..
	151	In primary school? (yeah yeah). Am, oh,
	152	they were great in this one, they were
	153	saying what do I need and what kind of
	154	person he was before he started; they
	155	were v- they were really helpful (okay).
	156	Am, but I suppose, that’s the thing, it’s like
	157	.. If you have a u – if there’s a unit (yeah)
	158	near - I suppose you’re lucky to have a
	159	unit somewhere (yeah); you have that
	160	choice but .. then again, I don’t mean to
	161	be – be disrespectful to other people (yes)
	162	but you’ve got to see who’s going there
	163	(yeah) before you make the choice (yeah
	164	yeah). I suppose, you’ve to think about
	165	that too (yeah)going to mainstream but ..
	166	you know you have to ch.. be aware of
	167	other kids needs before .. (yeah) before
	168	em ..

	169	Was there a bit of thinking, so, like when
	170	you're saying choice – bit of thinking had
	171	to go into it all (yeah) like about .. yeah,
	172	what was the best (you see) thing for him?
	173	Even though I'd much prefer him to go to
	174	mainstream because, you know, you like
	175	him to be kind of (mmm) am .. I suppose
	176	not be held back in any way .. you think
	177	(mmm) .. you know, it's still a bit of tossing
	178	and turning (yeah).. would the unit have
	179	been better? But no now s- now that he's
	180	started (brilliant, okay) now that he's
	181	happy and settled
	182	So up to the time he was starting, you're
	183	still kind of wondering how he'd get on ..
	184	And, I suppose .. there's – there's a bit of
	185	stigma as well attached to the unit.
	186	They're the kids that go to the unit, even
	187	though, like ... am, you know they'd have
	188	their – their own friends but still they're –
	189	'the unit' (yes, yeah yeah), do you know
	190	(yeah yeah yeah) which I don't like, but I
	191	suppose it's only now th- th- soon, I
	192	suppose most schools will have a .. (I'd be
	193	hoping) Yeah (yeah yeah) .. just even the
	194	term: 'the unit' (yeah yeah yeah) (half
	195	laugh). And you can hear parents talk
	196	about it – oh that he's one of the kids
	197	going to the unit (yeah yeah) they'd be
	198	saying .. (yeah). If I have that – especially
	199	it being such a small town, you know – if
	200	my son goes to 'the unit', he'll always be
	201	the kid that went – you know (yeah). It's
	202	tough that way (yeah yeah). So, I'm glad I

	203	had the choice that he .. (yeah) was able
	204	for mainstream (yeah, that is brilliant,
	205	yeah).
	206	Yeah, yeah, am ... What kind of .. like, he
	207	doesn't get an sna (yeah) do – do the
	208	school put other things into place for him?
	209	like the .. you might for a child with autism
	210	that, say some of the visual supports or
	211	structures like that?
	212	He didn't need those, he never used
	213	PECS or anything (yeah, yeah, yeah)
	214	because he's quite good; he follows
	215	instruction quite well (yeah). Am, they
	216	were .. am, they asked me all this
	217	beforehand. I think it was March we had a
	218	meeting and they said what would I like
	219	and I said let's just see how he goes
	220	(yeah) because he is quite (yeah) .. he's
	221	good with instruction, do you know he is,
	222	and he's .. am, he-he likes to learn as well
	223	(yes) which I knew would be a great
	224	advantage for him (yes yeah) and he's
	225	quite am, m- yeah, that motivates him.
	226	and, you know, being first and the best
	227	and (laughs) he's very motivated by being
	228	good (yeah, so there's no worries)Yeah.
	229	And in terms of transition – starting him,
	230	getting him ready, like, what kind of things
	231	did ye do or did ye find helpful?
	232	I suppose I found really helpful, as in he
	233	was going to <special preschool setting>
	234	so five mornings (yeah) and then they do
	235	a kind of transition programme where they
	236	bring one of their tutors over to the

	237	playschool and an I was lucky that the
	238	playschool he went to is attached to the
	239	school, well next door to it (yeah) so most
	240	of the kids who go there move on to the
	241	class so he was mixing with his
	242	classmates (yeah) all last year (yeah)
	243	with-with the aid of the tutor (yes) and she
	244	could tell me then, you know am, where
	245	he had problems or not problems (yeah),
	246	you know (yeah), he kind of .. she said he
	247	has a good memory for retaliation so if
	248	somebody takes a toy off him, it might
	249	take him a few hours (laughs) (just to get
	250	over it) so they'd have to watch that, you
	251	know, that he (yeah yeah) yeah. There's a
	252	few little things that was great pointers
	253	(yeah) and (yeah yeah) so. And again I
	254	think she-she did a fairly detailed report
	255	then so I was able to pass that on to the
	256	teacher. But the fact that he knew most of
	257	the kids and they were literally moving
	258	next door (so that was a..). it was a great
	259	(yeah) start for him you know. Really it
	260	couldn't have been any easier for his
	261	transitioning (yeah). Really lucky (yeah).
	262	So you (yeah), you kind of .. It maybe was
	263	easing for ye in a way as well, you know
	264	that (yeah).. maybe it took the worry away
	265	from that a bit.
	266	Definitely because I knew he could, say,
	267	now stand next to X, Y and Z, you know
	268	(yeah yeah) and there was still new a few
	269	pe – a few new people – so he could say,
	270	'look they don't know anyone at all' (yeah).

	271	He was .. and actually this school were ..
	272	they do a great s- they have – they call us
	273	parents in in maybe last April and they
	274	gave us a pack for starting (mmm) school
	275	and photographs and they gave us a list
	276	of things to prepare the child over the
	277	summer, you know, (yeah) you know, get
	278	them used to doing, say twenty minute
	279	activities (yeah); move on (yeah) like they
	280	do in school (yeah yeah). And then
	281	another day, they brought the kids in and
	282	the tee-mi- the teacher they were going to
	283	have took them for an hour into the
	284	classroom that they were going to be in
	285	and they did a few songs.
	286	This is during the summer?
	287	Over the picture, yeah, I think it might
	288	have been the end of June, you know
	289	(yes) before the kids broke up (yeah
	290	yeah). Yeah. (okay). And they all had their
	291	.. she gave them labels in pre-preparation
	292	for bringing these back in September, you
	293	know: these will be on your books and it
	294	was really ah .. you know, kind of
	295	seamless transition (yeah). They really put
	296	th- you know, put a lot of effort into it.
	297	Yeah yeah, that must have helped, I think
	298	(I know) yeah, yeah. Was he excited
	299	about starting school or what did he think
	300	about it?
	301	He was and it especially helped that he
	302	had an older sister going there and he'd
	303	like to see her going in there, and she's -
	304	she was so happy in there (yeah), and it

	305	was just natural that he'd follow suit (yeah)
	306	then, you know, and go in there (yeah).
	307	And plus, he – he did make a few good
	308	friends last year in the playschool (yeah)
	309	and they were all starting together (yeah)
	310	and he just couldn't wait to get in, cause
	311	the s-school is lovely, you know. Nice
	312	playground and (yeah) visually it's lovely
	313	and he just couldn't wait to move up
	314	(yeah) Yeah.
	315	Wow, that's great. Was there anything
	316	you'd have done differently or you'd have
	317	changed, or..?
	318	Pause. For the- for the getting ready for
	319	primary school?(yeah) I sometimes think
	320	should I have put up a fight for the sna?
	321	(okay) because it's a l-, it's a worry, but I
	322	think .. and then you know that it's re- I'm
	323	really, I'm still a bit torn (okay) because
	324	then he'd have probably have it for the
	325	whole school and, like (yeah) do I want
	326	him to – you, know is it better for him to
	327	have a harder start on his own (yeah) and
	328	get these kind of skills on his own (yeah
	329	yeah) because he has had two – two
	330	years, you know (yeah) in the preschool
	331	and that's all been one on one (yeah) so. I
	332	think, but am, now that he's settled in and
	333	I'm pretty sure I made the right decision
	334	(yeah yeah) Yeah.
	335	Do you think it's different, like for you, than
	336	it was for oth- you know, other parents?
	337	With him starting, do you think it's different
	338	to .. kids who don't have autism? Do you

	339	know, for you as a parent?
	340	It's a worry that he will regress, you know
	341	and it was such a .. because he's had the
	342	one on one and he's going in, is he going
	343	to (yeah) act out fine, you know, you know
	344	or (yeah) to lose some of the skills he's
	345	picked up or (yeah) ... do you know,
	346	things like that.. (yeah yeah)is it a bit more
	347	of a worry? (yeah yeah). Pause. I don't
	348	know because I've been preparing for this
	349	for two years. I think I've put a lot of work
	350	in and (yeah) as soon as .. I'm so – I'm so
	351	happy with the school and (yes)like, am,
	352	the feedback all round, you know, from
	353	say the – the <health services> who've
	354	been working with him, not (health
	355	services>- <multidisciplinary service> now
	356	(yeah). Yeah, they were - they've worked
	357	with the school and they were happy with
	358	it (yeah) and his preschool worked .. with
	359	the particular school (yes yeah). It was the
	360	best choice I could have made, you know?
	361	(yeah) I'm just - I'm really happy with it.

Appendix 14

Key words	Page/line	Themes	Superordinate themes
		Cormac's issues, difficulties with change, difficulties with noise, our awareness, Cormac's feelings, risk (hard to know what to do sometimes), preparing him for the future, what I want for him	About Cormac
<p>He'd be full of chat ... but then you'd see, like social, he'd be looking away (okay) and like, speech-wise, he's always been grand (yes yes) which then is .. obviously good in one way, but then his communication wouldn't be great (okay) which can fool people; and it fooled us for a long time as well</p> <p>big issues from a baby were – he still can't bite (okay) – he can bite now, but he can't bite, chew and swallow (yes); he can bite and swallow, so .. (okay) and fierce sensitive to touch, like, supersensitive to touch</p> <p>at two, do you know, we went to a paediatrician ourselves, privately, (yeah) because we were told by the GP anything publically doesn't start til they're two (okay) and we knew from the textures of the food (yeah), it wasn't something typical</p> <p>we always said, even to the paediatrician, 'could it be autism?' (yes) and we did the GARS test then and all that – he was three – and they still said, 'Look we're not sure' (yeah) so at four, we noticed at preschool, like, I had to keep asking the head 'what do you think?' and she kept saying, 'well the social isn't there' ... we noticed he played</p>	<p>1.4</p> <p>1.14</p> <p>1.18</p> <p>2.30</p> <p>244</p>	<p>Issues and strengths</p> <p>Issues with physical as well as social</p> <p>We knew something – took him early privately Not typical</p> <p>Always said it could be ASD – asked professionals</p>	

by himself			
so then the whole .. (okay) whatever .. autism was diagnosed (yes, okay) in September then (yeah). But we always, kind of, in the back of our minds .. we always had an idea (okay) or do you know, we always questioned it	2.42	After a time, diagnosis of ASD on top of SPD Always suspected, questioned	
when he went in there, because everything was structured (yeah), he didn't adapt well at all	3.71	He didn't adapt to change	
a big thing then kind of that came out was actually noise drove him mad	4.84	Noise sensitivity – big realisation	
just very upset and just wouldn't sit down on a seat and just .. for him, obviously wasn't a nice experience anyway	5.121	Not nice for him, couldn't sit Big impact of change in environment	
(Psych said) he's so out of sorts now (yes) to then move him back to a room with all different people (yeah) ..' he said 'that could, like just double (yeah) the issues'	8.188	Risk of moving him again	
if he was upset with one kid, he'd never want to sit with them again, do you know? (yeah yeah). He used like (laugh) copy the teacher a lot, or do you know, not seeing the parent or the adult / child thing as well (yeah) so, some things like, he'd get in trouble for thing that you'd have to be careful of	23.568	Issues with social understanding	
we go out and we go to certain places with Cormac just to make sure, like, we've <local town playground> , they've a little play area – it's a nice small area but our main thing is, we go over there, so like, they obviously go over to see the trains, but our main thing is to get Cormac in there, that there's never that many kids (yes) – there's only three or four (yeah) kids and just try and do natural play with him	33.805	Working on his issues at home	

<p>so all the time you .. you just want them to be like any other typical kid</p> <p>You want him to be able to go to the shop, do you know, ride his bike, do whatever, like. So at the end of the day, and he's right, you just want him to live a normal life so you want them just to be in with kids that they can just (yeah) learn, do you know, not be kind of s- it's almost like a segregation thing</p> <p>we've to teach him everything (yeah). With <i>every</i> kind of <i>physical</i> thing (yeah) you almost have to have a mantra (yeah) do you know, it's like it doesn't sink in til you kind of go .. like, you could sit down now and his food in front of him, and he'll sit there for a while and you'd have to .. just a trigger to kind of just go am, 'lift your spoon' and when we were teaching him how to eat because he had such a phobia with food .. like we used to do the hand /over method (yeah yeah) and I used just do 'down and up and into your mouth, (yeah) down and up and into your mouth' and just .. We'd to do that for about two years (okay) til .. just the routine .. because otherwise, he'd just .. he could just go like that and that would be it. It was like just constant (yeah) reinforcing (yeah yeah) with the words what that the action was because (yeah) motor planning would be so poor</p> <p>so you've to try and pick your battles (yes) then uh do you know (yeah) but lots of things now and I'm saying 'you can't bring toys to big school' (yeah)do you know, 'you have to listen to your teacher (yeah) and respect' so I've to do now .. I've tomorrow now I have to do everything tomorrow.</p>	33.817	What I want for him – just to be like any typical kid	
	34.828	Want him to be able to live a normal life	
	40.985	Effort, constant teaching, every thing Things other children do naturally and automatically had to be broken down and reinforced on a constant basis Poor motor planning	
	49.1220	Pick your battles with Cormac, trying to prepare him	

		Waiting for services, took the initiative, uncertainty about future	Time
Fooled us for a long time (good speech)	1.10	For a long time didn't see issues with communication	
we went to a paediatrician ourselves, privately, (yeah) because we were told by the GP anything publically doesn't start til they're two	1.18	Didn't wait for community; didn't waste time	
even going private, we ended up at the same route but probably that bit quicker	2.26	Quicker to go private	
'how is he going to be able for school (yeah) if he can't even sit in preschool? (yes) with his other school friends or preschool friends?'	6.137	Worry about how he'll cope in the future	
we went from thinking he just had sensory processing disorder then to going (yeah) 'do we have to send him to a special school?' (yes) within a week (yes) do you know what I mean, like. We didn't even have time for it to sit to go (yeah)'right' and it was just very emotional; for a month any time I was thinking of stuff I felt like crying (yes) do you know, because I was going, do you know, just in the long run (yes), 'is this the way our life is going to be now, that we're kind of going to schools in <town> or, or do we have to look at wor- like moving? Do you know, there's a bigger picture (yes) in all of that then	11.255	Suddenly – special school within a week Didn't have time to sit and take stock For a month very emotional Long run – bigger picture, uncertainty about future	
we've the big issues from the move' (yes) and at that stage, we had refused the ASD unit (okay) so then I was saying 'oh my God, what are we after doing now?'. The preschool don't know how to deal with him, and the ASD unit, or the ASD placement, is gone (okay) so what are we going to do?	13.301	Timing – having refused unit, problems started	

<p>.. it was all on timing too, of the diagnosis that .. we were going into the preschool so (yeah) do you know there was no kind of thing of 'oh, you should be looking out for ASD units or ..'</p> <p>He'd have none of that (yeah) if he didn't have that time</p> <p>Good days and bad days</p> <p>the whole diagnosis and whatever ... that took me a good while (okay) to get my head around it</p> <p>because he's always been sociable, it's more now, as he's getting older you can -, do you know, it's becoming more obvious</p> <p>just constant (yeah) reinforcing</p> <p>it took us from September til March to get a home tutor which was so frustrating as well</p> <p>I think as time goes on anyway you realise .. I think the first few years it's all so much. As time goes on, do you know it's just like, do you know we can deal with it (yeah). It's not .. and, eh, like that things arise just day to day anyway .. (yeah yeah yeah) it's not that .. it's like anything, if you think of the bigger picture, it's like 'Oh Jesus ..' (laughs) (yeah) 'break it down, it's all right'</p>	19.474	We had him there before diagnosis so timing was not ideal – then recommended he stay there	
	23.564	Needed time – one-one from tutor to get him prepared	
	24.597	This is how it's going to be	
	28.689	Time to get head around diagnosis	
	38.951	As time passes, social issues are becoming more obvious	
	40.1000	All the time it takes to teach him	
	43.1056	Waiting to get HT – frustrating	
	56.1471	As time goes on you know you can deal with it. So full on in first few years. Break it down – panic if you think of bigger picture, look too far ahead into the future	
		Team, school, support and advice from team – for school, for selves, limited resources, informal supports, harnessing own resources	Services, supports

so from two he's been with the PHS on the <team> (yeah) which has been brilliant	2.27	Team has been brilliant	
it was am, it was just good that we were in the <team> and it all ran quite smoothly in the diagnosis and we're at a stage that going into school (yeah) we have the diagnosis, so he has his SNA (yeah) because that's what we were fretting quite a bit about with the <team> was him going into school (yeah) because we knew he wouldn't sit down and manage by himself	2.48	Were with team, then smooth diagnostic process Fretting about him managing by himself but dx means he has sna	
the <team> in <town> were brilliant (great yeah), yeah, there was a really good OT there ... she was brilliant, and, like, she was very .. kind of, frank with you (yes), do you know, if you asked, she'd say, do you know, 'well, these can be certain traits' and just certain things	3.62	Team great, great OT, helpful, frank	
(When he went to toddler room) he didn't adapt well at all (okay) but they were great; like I'd just ring and she came out and she did, do you know, the little ... visuals	3.71	He didn't adapt and she would help	
we had to get <name>, the psychologist (when things went wrong for Cormac in preschool) So my husband said 'Let's ring <psychologist ASD> and talk to him about it'	4.91 7.171	Able to ask psych for help when things went wrong and he came out	
the manager's lovely and she's actually a local girl and I think they were great because Cormac was there since he was two. They were used to him, they were used to me and they were kind of willing to help, even though they were up against walls, which I felt sometimes .. like, they really did as much as they could	13.309	Support, relationship, used to each other, they wanted to help, they knew him since he was a baby, used to me	
he needed the help really around all fine-motor,	14.344	Needed help at certain particular	

concentration, sitting down, all that stuff		times	
because we go to OT privately, in <private Ot Practice> as well, do you see, he needs it. It it's (yeah)yeah, I know it's an option, but he <i>needs</i> it	17.407	Have to access services privately, an option but he needs it	
obviously if you're getting somebody now and we're paying, it would be great if we had somebody with ASD experience or had worked around kids with ASD	17.416	Ideally someone supporting would have experience of kids with ASD	
she was fabulous, absolutely brilliant, like (yeah). Am, and from the-, he just came .. like, before he left school, he was back where he was (right) and socialising and like ... she was just fabulous; she really was fabulous	17.421	Brought him back to where he was before he was moved	
but our recommendation anyway was to stay where he was (yeah)	20.478	Recommendations mentioned a number of times	
And even, he had no OT since last May ... and his fine motor skills like are terrible (okay) so that's why we've to go private ..	27.662	No public service so had to go privately because he needs it	
at least they listen, (yes) do you know, whi- which, at the end of the day, I find is the main thing (yes, yeah) so, you have to take the emotion out of it (yes) somewhat (yeah yeah), just get a thick skin (yeah) to try and push (yes); because resources are limited in every area	28.696	They listen, which is the main thing, have to take emotion out of it, thick skin, push Limited resources	
we were told, am, by the psychologist that of all the difficulties, am, you really want to focus on the social because he might be clever enough and what you have, but you don't want him then (yeah) sitting up in the room all day by himself and not interacting (yes) or just like, in general, he won't survive	33.821	Need to work on his issues, prepare him for the future – survival So he won't be isolated We support him	

and just have (yeah) ah, support (yes) and family around you because while you're doing all your meetings and your services and all (yeah) that like, you need people to mind your kids	36.896	You need informal supports – family and friends	
I used to have to get people down to mind <child 2> and it's only now since they're doing the <disability services> it's <local town> so I've a few friends (yeah) now I can ask (yes) because (yeah yeah) you can ask them to mind for two hours as opposed to (yeah yeah) the .. we were going to <town> ; it was a three and a half hour trip (yeah) and if we went over then, I'd have to try and feed Cormac over there so it ended up four / four and a half hours (yeah) to do a one hour stint (yeah) so at least the services are nearer now	37.904	Having services and then trying to access them, harnessing own resources, logistics	
hopefully they'll get the people (laughs) with it (yeah) because like as much as you can have a lovely building (yeah) it's it's ..because like even with the <team>, there's never been more .. there's four people on the team, the psychologist, the physio, you probably know yourself, there was never more than two available at one time (yeah. Like, for <child's> first year there was no OT	37.918	Effort, taking him there, getting other child minded, using own resources as well, strain oft this	
As good as the team is, it's only as good as what's available (yeah, in fairness) to you, do you know and you just have to .. (yeah) that's the first and eh, that's why it all boils down .. it all boils down to the resources ... if you're a practical person and can realise that (yeah), like that we're lucky enough that we can afford now to send Cormac to OT (yeah) but if we didn't, he still has had no OT	38.932	Now services are nearer ... but ... team numbers are low, not enough	
(social worker) she got back to me a few weeks later and	44.1099	Can't guarantee access to services or team composition, limited resources Don't take it personally We're using our own resources or else he'd get nothing, element of luck also SW got back with a name (support) Element of luck	

<p>said a girl had just rung in (yeah) willing to do home tuition ... just by pure luck (yeah) we were able to start .. she was able to start the week after</p> <p>But like she helped us (home tutor)</p> <p>she helped us (yeah) get to the stage where he was willing to write (yeah) and do you know, just the whole .. and like, lots of colouring (yeah) and like, doing games with him and (yeah) what you have so, that as well was a huge thing, like I don't think he'd be where he is without her either so (yeah) I think, yeah, if you're in preschool and you're struggling, you definitely need home tuition</p>	<p>46.1131</p> <p>46.1151</p>	<p>Reassurance, advice</p> <p>He wouldn't be where he is without her</p> <p>Recommend having HT if you're struggling in preschool</p>	
		<p>Concerns, feelings – relief, practical v emotional, feelings v thoughts, preparation, uncertainty, fears about him fitting in, hopes for school, support with transition</p>	Starting school

because that's what we were fretting quite a bit about with the <team> was him going into school (yeah) because we knew he wouldn't sit down and manage by himself (yeah). We we always knew that so we're relieved now, in another way, obviously not with the diagnosis (laugh) because nobody wants that (yeah) but at least we have it for the help he needs (yeah) which is a good thing, like, you know (yeah yeah) so, from all that point of view, it's been a very good experience	3.52	Worried about school but diagnosis has meant help and relief for us – don't want it but he needs help so good in that way	
we've the big issues from the move' (yes) and at that stage, we had refused the ASD unit (okay) so then I was saying 'oh my God, what are we after doing now?'. The preschool don't know how to deal with him, and the ASD unit, or the ASD placement, is gone (okay) so what are we going to do?	13.301	Uncertainty, panic? Blaming selves, doubting selves	
(the fact that he has a headstart on academics) should make it a little .. that bit easier now going into school, do you know that .. (yeah yeah); you hope well , hopefully	23.560	Hoping he'll be prepared	
now for school, we've been out to the school and we've picked out a desk, just from the experience of preschool, we realised now that (yeah) he needs a chair .. that they have .. the way it's done in school	24.576	Preparation for school	
but even now, I'm thinking 'I haven't rung anyone yet for school' but they said they will come out in the first week (yes) but I .. like, since yesterday, I was going 'I should have contacted them'. You've to be one step ahead (yeah) to try and get their (yeah) time and their attention (team)	27.652	Concern about getting team out, I should have...	
but I want them (the issues) known from the start' (yeah yeah) do you know, so everything is in place from when he	31.777 253	I want everything to be prepared, have everything in place not trying to deal with	

goes in (yeah) not that all the difficulties arising then where we're trying to deal with them one by one and tick them off and say 'oh, right'		issues as they arise (as in the past)	
everything has to be planned and then there's planning around .. do you know and there's so many appointments (yeah) and this and that then as well, like, that .. (yeah yeah)	35.860	Different life- everything has to be planned, busy with appointments	
and just by him and pure luck to a degree, he'll be going to <local school> which has three snas (yeah), has a good few resource teachers	35.877	Luck that he's going to a school with supports	
by kind of chance (yeah) we're lucky enough – we're near a school that has those kind of things available	36.888	Luck that we're near the school	
Oh he's all excited now, but that's j- .. he's very naïve (yeah) and very innocent sure God love him, he'll be all 'ooh wooh'	47.1172	He's all excited about starting Naïve and innocent (how I feel)	
(influenced by cartoon, he said)'oh I'm going to be really mischievous in school'	48.1179	Hoping he won't copy cartoon and try to be mischievous in school	
it'll be all the behaviours now when he goes in initially and at the moment, he's very frustrated. If you tell him something he doesn't want to hear, he can lash out (yeah) or do a face off now (yeah) or he'll go to slap you (yes). It's all just pure frustration	48.1183	Anticipating how he'll be – afraid he'll lash out	
you just kind of have to try and rein it in (yeah) because for a few days there we were like 'what am I going to do with this? Just starting school now (yeah yeah) and these issues are coming up' and they <i>will</i> in school because they'll tell him sit down and do whatever (yeah) and he's very	48.1196	Using strategies to 'rein it in' Uncertainty	
		Issues coming up	
		Headstrong	
		EB and strategies	

<p>like I met the principal myself first and sure you go through all the difficulties and (yeah) then when she met him she was like ‘after you hear all the difficulties you forget it’s just a little boy’</p> <p>I have no control whether or which (no) or no (no) yeah. Er, he’ll he’ll be grand in there (yeah) am. It was just a big class, that’s my – my main worry (how many is that?) 26</p> <p>He’ll have the sna and the resource hours and am (that’ll really help) yeah and I know actually two of the resource teachers anyway. They’re they’re from the area like (yeah)so (yeah) em, yeah the school will be grand – I’m not worried about that (yeah) it’s just more the behaviours and .. basically will he make friends? (yeah) that’s what you’re actually worried .. for all the other things you’re fighting for like at the end of the day you don’t want him to be ostracised (yes) or (yeah yeah) do you know not making friends (yeah) and feeling ..(yeah) do you know being bullied or bullying, do you know (yes) because he can be bossy in his ways (yeah) then to play (yeah) do you know you teach him something and then you realise ‘oh my God, he’s taken over the shop now (laughs) you go ‘right you can only do so much’</p> <p>they’re all things he’s just going to have to learn (yeah) and do you know (yeah yeah) .deal with it</p> <p>I suppose a big thing for me is that .. yeah, he’ll learn, but that he’ll <i>cope</i> around people and make friends. (yeah yeah). And, am, I suppose just be able to be a typical little boy as much as he can be. Not to sound whatever .. and that that actually to <i>be</i> that is actually a lot .. but not to be <i>too</i> different</p>	52.1352	No control Telling myself he’ll be grand in there; worry about class size	
	52.1363	He will have supports and school will be grand Not worried about it	
	53.1382	Worried about behaviours and will he make friends You fight for all the other things but at the end of the day – it’s up to the other children how he’ll fit in Being ostracised Worry about him bullying or being bullied	
	53.1397	He has to learn to deal with things, can’t do everything for him Hope for him in school and in the future	
	54.1405	That he’ll have friends and be typical, not too different (not stigmatised?) Not worried about education, worried about him fitting in,	

<p>so I can give him the time (yeah) to do his homework (yeah) and reinforce all that so we're not (yeah) actually worried about (yeah) educ- once I know what his homework is (yeah) that'll be fine (yeah). It's more (yeah) just learning about life in general and .. not standing out so much that he <i>is</i> the very different child, do you know what I mean</p> <p>in school if you fill.. if you're labelling him .. and I know it'll probably be apparent enough in school like: that they get help and what you have, like, so I suppose with school as well, that he's accepted, not tre- not treated differently because he has difficulties but accepted 'yeah he needs the help' (yeah) but that comes down to kids as well, do you know what I mean? As much as you can teach a child (yeah), a lot of it is social interaction and do you know, kind of unspoken things .. because he doesn't get it, you know like .. the unspoken (yeah) the looks, (yes) the .. do you know (yeah) he'll snitch on someone like, do you know, (yeah) and say 'oh you're talking' (yeah) or (yeah yeah) do you know and you're like 'Aw don't say that'</p> <p>I suppose from school really, you just want to make sure they're prepared for life; that they do, when they come out of school, have options of (yes), I'm not saying college, but they're options there to do stuff.</p> <p>the big thing for us is that he copes because his sensory levels <i>are</i> so (yeah) <i>over</i> the top (yeah yeah) that it's all about, do you know, bringing him down to the level where he can then (yeah) <i>deal</i> with it so he's not do you know, way up here (yes) trying to (yeah) deal with him either</p>	<p>55.1436</p> <p>56.1457</p> <p>56.1465</p> <p>57.1480</p> <p>57.1490</p>	<p>learning about life, not standing out, stigma</p> <p>Label gets supports in school Anticipating that he'll stand out a bit</p> <p>Want him to be accepted, not treated differently</p> <p>Depends on other children He doesn't get the social and this might make him unpopular, for example, he'll tell on other children</p> <p>Hopes for school, that he'll be prepared for life and will have options when he leaves</p> <p>Practical and immediate concerns – hope he'll cope with his sensory issues because he finds it difficult to self-regulate</p> <p>Knows some kids going so that might make it easier – hope</p> <p>Had to be proactive with school</p>	
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<p>he knows some kids (yes yeah) as such which am, hopefully, will make it easier for him</p> <p>Like the one thing now, I found was, like, <i>going</i> to school. Like, I had to say 'can we come out and take photographs?' Am, 'can we come out and meet the teacher?'</p> <p>Just to be prepared</p> <p>You <i>have</i> to prepare for going into school</p> <p>I'm going to have to do out a chart- just even a car picture, picture of the school, do you know starting school (yeah) and do you know, pictures of 'I'll be back' or do you know (yes) hometime and those kind of things (yes yes) so, it'll take probably a while for the resource teacher or whoever the sna to do those charts up and stuff so I'm conscious that I need to have something at a higher level (yes) going in there because just walking him into the door, just going 'there you go, buddy, just won't work' ... there's nothing in place <i>before</i> they go in. It's up to you to go .. to approach them, and it's up to you to put all your things in place</p> <p>I suppose it would have been nice .. if somebody from the team (yeah) had organised something or, in fairness now, could help them (brilliant, yeah) <i>but</i> they're not provided by anyone to the school, do you know what I mean? So.. (I do, I do) .. they're things I just need (yeah). I like .. that could help them and help me.</p>	<p>58.1498</p> <p>58.1502</p> <p>58.1504</p> <p>59.1523</p>	<p>– offer to support, put strategies in place, preparation</p> <p>I'll have to have all the preparation done for him because it will take them a while to get organised, I'm conscious (I know)</p> <p>Can't take anything for granted</p> <p>All the resources that are necessary Plan for how to proceed</p>	
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Findings: Maria

1 Introduction

In this chapter, I will present the findings from Maria's interview beginning with a narrative account followed by an exploration of the subordinate, superordinate, and overarching themes in her transcript. I will make reference to the hermeneutic circle and will include describe my reflexive process in relation to the interview.

2 Background to Maria's interview

Maria talked about the experience of sending her son, Paul, to school. Paul was aged five at the time of the interview and was due to start school the following September. Maria had gone through this process already with Paul, as she had tried to start him in primary school the previous September. She had taken Paul out of school after a month and put him back in preschool as he was having difficulties settling in primary school and the staff there seemed unable to cope with his needs. Paul was diagnosed with autism spectrum disorder (ASD) a month later. Maria felt that part of Paul's difficulty settling was due to the large number of children in the class and the paucity of **support** available to him. She told me she had offered the school support but she felt they hadn't taken her up on her offer. Maria felt that Paul's experience of starting school led to a regression in his toileting skills. He was fully toilet trained before starting his new school but at the time of the interview he was wetting himself several times a day.

Paul has an older brother, Donal, who also has a diagnosis of ASD and Maria talked about her experiences of dealing with school staff around Donal's education during the interview. Her experiences with Donal had an impact on how she felt about Paul starting school. This was evidenced by Maria's references to her experiences with Donal and to things she had learned through her experiences.

3 Linguistic features

Maria was concise and clear in her narration of events. When talking about her own feelings, or her hopes, she sometimes used adjectives such as "little"; "a

little angry”, and “very” as in the case of “very frustrating”. In this way she gave salience to her feelings. In relation to her saying “a little angry” I felt she may have been minimising the feeling, for example, on one occasion, when she talked about her anger, she was referring to something that she found very frustrating, namely when the school principal asked her a number of times if Paul would be okay in school. Maria told me this made her “a little angry” as she found it difficult to understand how she was expected to answer such a question as she was not a teacher. I wondered if Maria’s anger may have related to school looking for reassurance from her even though they often did not listen to her. It is also possible that Maria’s anger was mitigated by her attempts to understand both other people’s perspectives and the way in which the school system worked.

4 Subordinate, superordinate and overarching themes

In this section, I will describe the subordinate, superordinate, and overarching themes that I identified in Maria’s interview transcript. An outline is provided in the table below.

Table 1 Subordinate, superordinate and overarching themes

Subordinate and superordinate themes	Overarching themes
Relationships with other people <ul style="list-style-type: none"> - Because I’m just their mum Professional v parent / education v experience - Conflict with other people - Building relationships 	Maria’s roles and relationships I’m young but I’m experienced
Maria’s depiction of herself and her children <ul style="list-style-type: none"> - Young mother, student, advocate - About Paul and Donal 	
Trying to understand Paul Trying to understand the system <ul style="list-style-type: none"> - Maria’s struggle to understand the system - Maria’s feelings about conformity Trying to be understood <ul style="list-style-type: none"> - Maria trying to be heard - Paul trying to be heard 	Understanding and being understood Why can’t they just understand?
Maria’s feelings about support <ul style="list-style-type: none"> - Support for Paul in school - Support offered by Maria to the school - Changes in support for children with SEN Maria’s experiences of preschool and school Maria’s feelings about Paul starting school	Maria’s experience and expectations of transition

4.1 Maria's roles and relationships

This overarching theme was made up of superordinate themes "Relationships with other people" and "Maria's depiction of herself and her children".

"Relationships with other people" comprised the subordinate themes "Professional versus parent / education versus experience", "Conflict with other people", and "Building relationships". The superordinate theme "Maria's depiction of herself and her children" comprised "Young mother, student, advocate", and "About Paul and Donal".

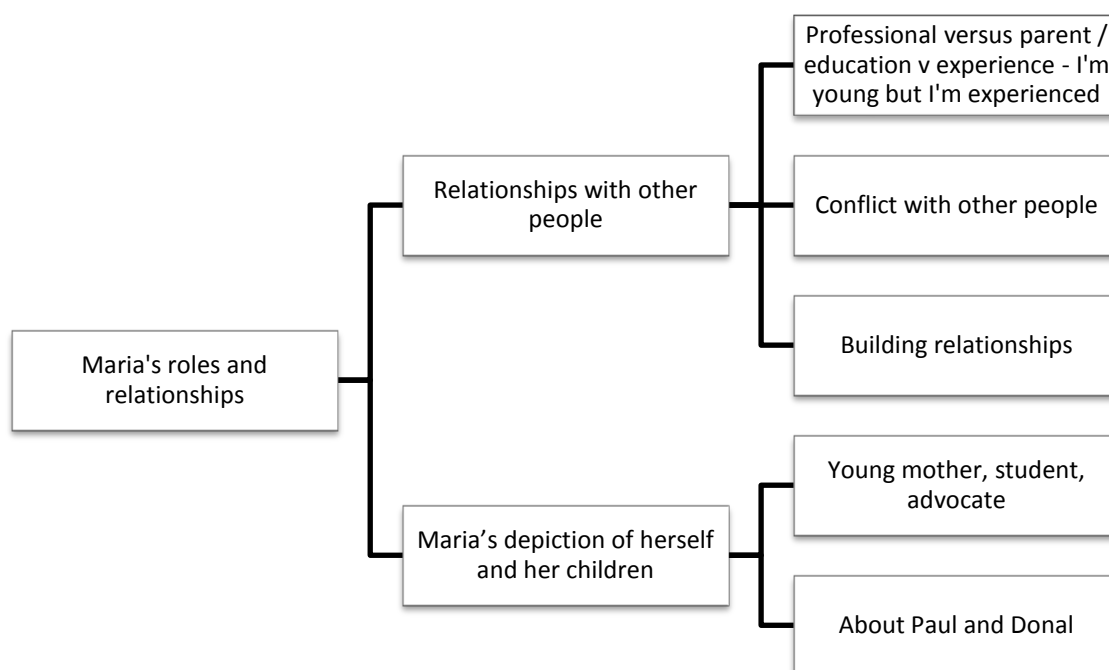


Figure 1 Overarching theme "Maria's roles and relationships"

4.1.1 Relationships with other people

This superordinate theme covered a number of subordinate themes including "Professional versus parent / education versus experience", "Conflict with other people", and "Building relationships".

Professional versus parent / education versus experience

Maria talked about the dynamics between parents and professionals. She knew how to work with her sons and had experience as a parent but didn't feel that staff in school appreciated this. She felt that if she was a professional, staff in

school would listen to her, for example, when she had brought professionals into the school, they were more likely to be listened to:

.. the coping mechanisms and things that they put up, ah, was exactly what I had told the school to do but they weren't doing (P.13, L.324).

I do get the feeling if I, I don't know, if I had a child psychology degree or something, they would be begging me for advice but because I'm just their mum, that doesn't seem to count (P.14, L.335).

As mentioned previously, Maria also talked about finding school staff intimidating.

Conflict with other people

Maria talked about areas of conflict with school. She did not have control over whether school would take her advice on board and felt she was essentially trying to "fight" for her child (P.22, L.544). The term "fight" seemed to encapsulate Maria's experience of the conflict she had with staff in school who frequently did not understand her and her children and with whom she had a continuous and sometimes, hostile, struggle to achieve her goals. She did not want to go back to the time when she had significant difficulties with school and instead was trying to "work with them" (P.10, L.241).

Maria felt it was critical for both parties to work together, "I think it's very important for parents and the teachers to work together .. I know how important it is because there's no way those teachers are going to know him as well as I do" (P.21, L. 520). Maria felt that her experience and knowledge as a parent was often disregarded and was acutely aware of the importance of imparting this experience and knowledge to staff working with her children.

Building relationships

Maria talked about getting to know staff in school, "I've been dealing with the boys' school for (a long time) so they understand me now and so I know it's just going to take time" (P.5, L.102). Maria felt that, for staff with whom she was familiar, "I get on very well now with (familiar teachers) where they .. just

understand my method and they understand how you work with my kids” (P.11, L. 263). Knowing staff in preschool “for many years, I don’t have a problem in approaching them” (P.4, L.95). It seemed that when Maria developed relationships with staff over time, good communication and mutual understanding also developed and this had a positive outcome for the children; she was able to communicate their needs to staff and staff were well disposed to take on board Maria’s suggestions and information.

4.1.2 Maria’s depiction of herself her children

This superordinate theme is composed of the subordinate themes “Young mother, student, advocate” and “About Paul and Donal”.

Young mother, student, advocate

Smith, Flowers and Larkin (2009) talked about identity as being a theme that is often encountered in IPA. Maria made references to her different roles during the interview. She was a mother, a student and an advocate for her children.

Maria described herself as “very young” and alluded to perceptions she thought that school staff had of her, for example, when she felt they didn’t listen to her because she wasn’t a professional. Maria felt that if she had a degree, she would be empowered and would perhaps be listened to. She also presented herself as someone who, though not a professional, knew her own child and had valuable information for the school. She was validated when professionals made the same suggestions around supporting her children that she had already made. Maria talked about having grown since the time of her difficulties with school staff in relation to Donal:

I was very young then and I didn’t understand how everything worked. Now I understand it a bit more so I have that bit more confidence to go in and go “Listen ...” (P.13, L.307).

As a person, Maria felt that she was the kind who “If there’s something going wrong, I will feel the need to question why” (P. 22, L.528). She liked to sort issues out and did what she had to so that the children would be accommodated.

Maria talked about the practicalities of being a young mother who had two children with ASD and who had to essentially fight to have their needs addressed, “I dealt with the issues. It’s what I needed to do” (P.12, L.297). It was apparent that this was not her preferred mode of relating with school staff as Maria preferred to be open, communicative and supportive.

Maria seemed in some ways resigned to the fact that parents are not always listened to and that it takes time to build trust and relationships with school staff.

As a parent of children with special needs, Maria felt she experienced the “reverse” of what many parents of children with ASD experience; her son, Donal was better behaved at home and had issues in school which was not typical for children with ASD who tended to be well behaved in school but to have issues with behaviour at home.

As an advocate, Maria tried to make sure that her children had what they needed in school. She brought in professionals to talk to school staff about their needs and “that changed everything” (P.13, L.321). She had to change how she approached issues, “I’ve learned to do (work with teachers) the hard way” (P. 21, L.521) for the good of her children. Maria talked about having to fight for her children in a way other parents perhaps didn’t have to do. Maria had to remember Paul’s needs and had to remind people of his needs when they forgot. She described the tendency of people to forget the needs and issues with which her children presented, for example in the case of staff working with Paul, “People tend to forget that they (the children) don’t understand” (P. 6, L.142). She felt that school staff didn’t “seem to remember the basics (about working with children with ASD)” (P.8, L.177) and found this frustrating: “How can nobody remember the basics?” (P.8, L.183). Maria felt she was “having to continually remind them” (P.9, L.205). She told staff “He will be okay but you must remember he is a special needs child” (P. 9, L.211).

About Paul and Donal

This subordinate theme encapsulated Maria’s descriptions of her sons. Maria talked about Paul warmly, describing him as “charming” (P.1, L. 4), “very social” and “very clever” (P.1, L.11). She said it was hard to believe he was “on the

spectrum” (P.1, L.8). Paul is also “headstrong” and “determined” (P.14, L350) according to Maria.

Maria mentioned her older son, Donal in the interview. Donal had difficulties in school which led to him being aggressive there. This was out of character for him as he did not behave in this way at home. Maria felt that this was due to pressure to conform and lack of control in the school setting. From her account he seemed a very self-aware young person who had once said to her of his experience in school “Mum, I can’t do this anymore. All I can hear is negativity and I can’t do this” (P.13, L.305).

4.2 Understanding and being understood

“Understanding and being understood” was an overarching theme which encapsulated a number of themes relating to understanding others and being understood by others. Maria talked about multiple perspectives during the interview including her own perspective, those of her children, the perspectives of small children in general, and those of children with ASD.

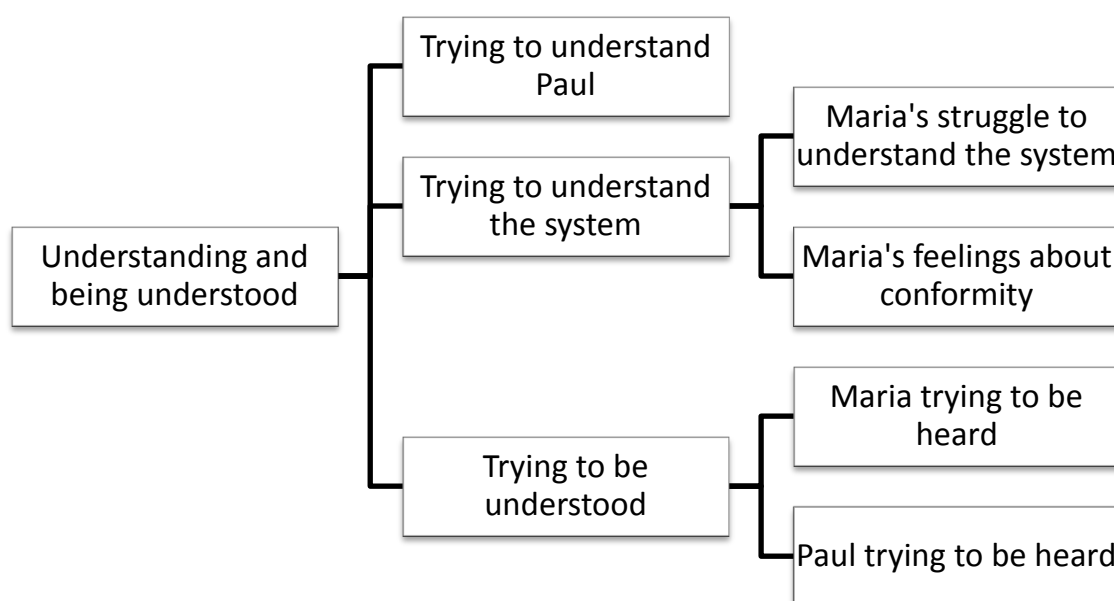


Figure 2 Overarching theme “Understanding and being understood”

4.2.1 Trying to understand Paul

This superordinate theme reflects Maria’s attempts to understand Paul as a child who struggles to understand things, who forgets things he should

remember, and who has contradictions in his presentation. Maria described Paul as a little boy who was in many respects a “typical five-year-old” (P.1, L.14). Yet when Paul began school, he didn’t cope and became “very emotional” (P.1, L.24) crying for Maria, and having difficulties following class routines. Maria talked about contradictions in Paul’s presentation. He was charming and social but he forgot the needs of others; he was excited to go to school when he started initially and went into school independently but when it was time to go home he wanted Maria to physically pick him up and carry him. When he regressed in his toileting and went back to preschool, Paul still asked to go back to his “own school” (P.18, L. 427).

Maria spoke of her ability to understand how to work with Paul. Though he was headstrong and determined, she knew the ways to get around him. She talked about the school’s understanding of Paul: “I don’t think they fully understand” (P.6, L.137). She expressed her difficulty communicating his needs to school so they would understand Paul’s issues and the ways in which to support him:

As much as schools want support and they want people coming in showing them how to handle situations, they kind of don’t like being told what to do, so you can give them all the information in the world, it’s up to them whether they use it (P.23, L.568).

Maria found it frustrating to have to “continually go back: ‘Listen, you need to understand’” (P.7, L.173). She found staff in Paul’s preschool more able to support Paul and more understanding of his needs and the needs of young children in general.

Maria had to continually remember that there are “different things that I’ll have to bear in mind for Paul that someone whose child isn’t on the spectrum wouldn’t have to bear in mind” (P. 19, L.462). The experience of having Paul was different to having a typical child. For Maria, there were more things to be taken into account.

Paul had issues with understanding the needs of other children and there had been “issues with toddlers” (P.3, L.59) in preschool when Paul forgot that hurting others wasn’t okay. Maria felt that children with ASD could sometimes

lash out in social situations when they didn't understand how to behave and she felt that other people "tend to forget that they (children with ASD) don't understand" (P.6, L.142). Paul frequently forgot things he was told and it was up to staff and Maria to remind him: "He forgets about not hurting others" (P. 3, L.62). He could get "so locked into what he's doing he forgets to go (to the toilet)" (P. 3, L.72).

Maria felt that Paul's lack of understanding in social situations could cause problems. She worried that he wouldn't get necessary support in school to help him understand what was happening around him. This was a concern because she felt that:

If Paul understands what's happening and he knows there are people he can go to that he trusts... he will settle, but if he doesn't have that security, it will get out of control (P.18, L.444).

Maria talked about the importance of her older son, Donal's, understanding what was happening in school:

He can just see it's all madness and there's no method but if he understands the madness, whether he agrees with it or not, he can go with it. (If) It makes sense and he understands why then he can do it (P.16, L.394).

Maria felt that all children should be helped to understand what's happening and that schools were not as responsive to the needs of young children in this respect as the preschools were.

4.2.2 Trying to understand the system

This superordinate theme comprised the subordinate themes "Maria's struggle to understand the system" and "Maria's feelings about conformity". It reflected her attempts to understand a system which was at times frustrating and fraught with contradictions.

Maria's struggle to understand the system

Maria had a very negative experience of school with her older son which she had overcome and now had a good relationship with the school in question. Maria felt that she had been very young herself at the time Donal had started school and “didn’t understand how everything worked. Now I understand it a bit more so I have that bit more confidence to go in” (P.13, L.308). She felt she had learned the hard way how schools operated and felt more able to deal with the school system.

Maria knew that schools operate under constraints of large numbers, have fewer supports and need to follow the curriculum but worried about the effects on small children of having to conform: “It’s such a high level of conformity .. some children could get lost” (P.21, L.508).

Maria had difficulty understanding why school sometimes wouldn’t listen to advice or why they wouldn’t take on board information she gave them relating to her son, “I don’t understand how a teacher can then turn around (having been given information and reports) and go ‘is everything going to be okay?’” (P.10, L.234).

Maria saw contradictions in how the school system worked, how the children presented in different contexts and in the schools approach to receiving support. She talked about the contradiction, which she referred to as a “catch-22” (P.23, L.569), where “as much as schools want support and they want people coming in showing them how to handle situations, they kind of don’t like being told what to do” (P.23, L.570). There was a contradiction in the fact that Maria’s expertise and experience as a parent was discounted by school staff.

Maria felt that primary school was a very structured setting which did not necessarily meet the needs of young children starting yet it was not structured in the right way for her children with ASD who would typically require a lot of structure in their environment.

Maria’s feelings about conformity

This subordinate theme described Maria’s feelings about conformity and Maria’s feelings about her children having to conform. Maria tried to understand the structures and systems in school, “I understand that in the primary school setting there’s a particular curriculum to follow and you have to get the work done so it has to be more structured” (P.20, L.484) but she was concerned

about the impact this had on small children who were expected to conform to this high level of structure. She didn't feel that young children should have to conform: "I don't really like the fact that children have to conform" (P.9, L.217) because the "severity of it is too extreme" (P.9, L.220). She felt it was unfair to expect a small child to conform to the level expected in school. In preschool, Maria felt that children "are given much more freedom to be themselves" (P.20, L.483). She worried that because of the "high level of conformity (in school) ... some children could get lost" (P.21, L.505). Maria felt that transitions would go better for small children if school staff understood their needs and fostered each child's understanding.

Maria explained that Donal didn't conform because he needed to control his environment and that he "fought the system quite a lot" (P.15, L.371). She explained, however, that when he understood the system, and knew why things had to be a certain way, he tried to conform. For Donal, conformity could lead to a lack of control, which could lead to anxiety and aggression.

In a sense, Maria was also fighting the system in her own way by asking for supports and by asking that the system change to accommodate the needs of her children.

4.2.3 Trying to be understood

The superordinate theme "Trying to be understood" comprised the subordinate themes "Maria trying to be heard" and "Paul trying to be heard".

Maria trying to be heard

Maria talked about the importance of good communication in catering for the needs of a child with ASD. She talked about a flow of information between the people caring for the child and how important this was for the child's security:

With children on the spectrum, it's again one of the basics ... structure is what works, so you need it to flow between home, professionals, school, if you need it – to flow. Obviously there will be slight differences because they're different areas .. but if everybody is working together, then the child has the security of knowing "Everybody knows how I work" (P.23, L.575).

Maria showed evidence of the hermeneutic process in her reflection on what children with ASD felt: “Everybody knows how I work”. She felt that when “everybody is working on the same page” it was “brilliant” (P.23, L.566). Sometimes communication was lacking as in the case of the school which did not allow her to view the policies unless she was on the premises by prior appointment. This school did not publish its policies on its website and Maria found this lack of transparency and openness difficult to understand.

Maria felt that she hadn’t been listened to by the school in relation to Donal. She felt that if she had been a professional, staff in school might have listened to her. As a parent, she had a wealth of information on her child but frequently this was not taken on board by school to the detriment of her child’s experience in school. Maria used the phrase “Listen...” a number of times as if to show how much effort she needed to put in to make herself heard: “Listen, whether you like what I’m saying or not, go with me” (P.13, L.310). Maria felt frustration that she had to “sit there with the teachers trying to explain” (P.5, L.118).

Maria had experience both of being a mother and of working with young children. Despite this she felt school did not seem to value her knowledge and experience. She gave advice to school but it wasn’t until she involved professionals on her sons’ behalf that things changed completely. She worried about being heard by school: “It’s whether or not they’ll hear me or not; that’s what worries me” (P.18, L.442).

There had been misunderstandings between Maria and school in the past which had led to difficulties between the parties, culminating in a difficult meeting with the board of management and their legal representative. Relations at this point were strained and very stressful for Maria. Maria described being misunderstood by school:

I find the schools tend to nearly take offence to that (being asked why something is going wrong), almost like I’m trying to shift the blame onto them, instead of understanding, I’m not trying to get anyone into trouble here – I’m trying to find out exactly what’s going wrong so we can fix the problem (P.22, L.529).

Maria felt that school staff understood how she operated and she was more hopeful that they would listen to her in relation to Paul's needs.

Paul trying to be heard

Maria talked about interpreting Paul's behaviour to find out what he was trying to communicate as sometimes he was not able to make himself heard verbally. She noted that Paul liked to be heard and that "he'll do what he has to do to be heard" (P.21, L.515). Maria was an advocate for her children in the way she interpreted their behaviour and communicated their needs to school staff.

4.3 Maria's experience and expectations of transition

This overarching theme related to Maria's feelings and expectations around Paul's transition from preschool to school and her feelings about this transition for young children in general. It was comprised of the superordinate themes "Maria's feelings about support", which was composed of the subordinate themes "Support for Paul in school", "Support offered by Maria to the school", and "Changes in support for children with SEN"; "Maria's experiences of preschool and school", and "Maria's feelings about Paul starting school".

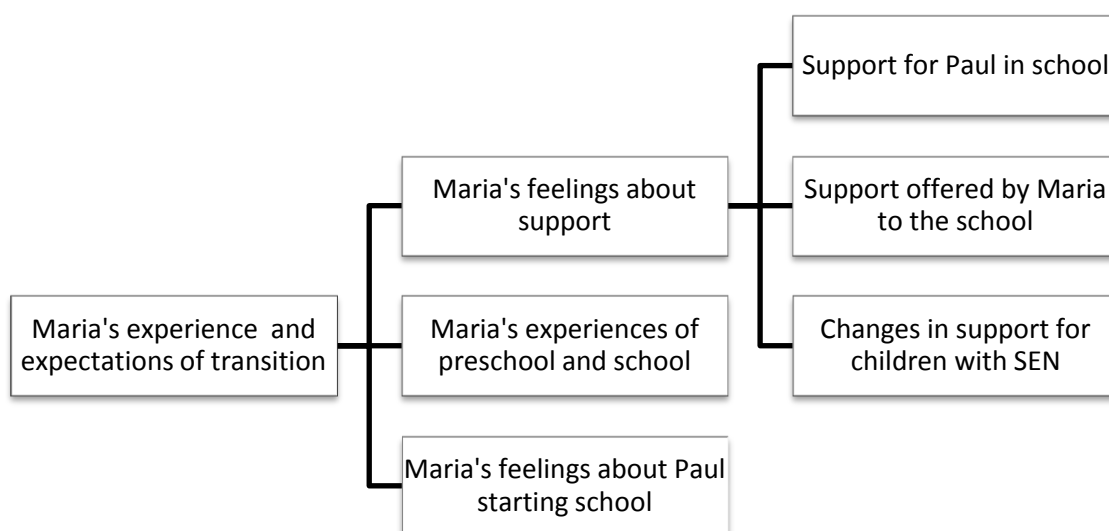


Figure 3 Overarching theme "Maria's experience and expectations of transition"

4.3.1 Maria's feelings about support

This superordinate theme was made up of subordinate themes “Support for Paul in school”, “Support offered by Maria to the school”, and “Changes in support for children with SEN”.

Support for Paul in school

Maria felt that if Paul “has the supports he needs, he’ll be fine ... it’s whether or not he’s going to get that” (P.18, L.449) indicating her feelings about the benefits of support and the uncertainty about whether he would get the support in a time of economic austerity and cuts to resources and support. Not having support had put Paul at a distinct disadvantage when he started primary school initially and he had to leave after a month.

Support offered by Maria to the school

Maria told me about a survey she knew of into school perceptions of support for children with special needs. A lot of schools in this survey “were complaining that there wasn’t enough support (for the schools)” (P.7, L.159). Maria had offered her children’s school support and had brought in professionals and felt that, paradoxically, though schools asked for support, they didn’t like to be told what to do.

Changes in support for children with special educational needs

This subordinate theme represented Maria’s description of changes in support for children with ASD. She felt it was a “different world to when my older son was diagnosed .. and there wasn’t much support then” (P.23, L.557). Even though Maria was worried that Paul wouldn’t get as much support as he needed on the basis of his diagnosis, he would still receive more support than Donal had when he had started school.

4.3.2 Maria’s experiences of preschool and school

Maria’s experiences of Paul’s preschool were largely positive despite issues Paul had there including getting “a little overexcited” (P.3, L.53). He presented with some behavioural issues towards other children when he forgot that hurting someone else wasn’t okay. Maria felt the preschool could handle Paul: “They find him easy enough to control” (P.3, L.51). She had known the preschool staff

for many years and didn't have a problem approaching them with concerns. She was able to discuss Paul's toileting issues with staff there and they were supportive of her. Maria referred to staff in preschool as "the girls" (P.24, L. 599) giving an indication of her familiarity with them. Maria felt the preschool staff understood the needs of small children and allowed them to be individuals.

Maria was worried when Paul started school the first time because of her previous experiences with Donal, who had found school very difficult. When Paul started school it became apparent that school "just couldn't cope with him" (P.1, L. 21). He was in a large class and because he did not yet have a diagnosis, he was not entitled to extra support: "So I was essentially told any time he does not conform you will have to come and collect him" (P.8, L.196). In relation to her choice of school for Paul, Maria was making a logistical decision. She would send him to the school that Donal attended as he was there already and it was near her home. She expressed that it wasn't necessarily her first choice and that she would have to "be careful with that school" (P.10, L.238) because of her history with staff there.

Maria talked about finding school staff harder to approach than staff in preschool. She felt they weren't "too keen to listen to the parent's advice" (P.5, L.101). She felt that over time, school staff had developed an understanding of her through her contact with them in relation to Donal, "they understand me now and so I know it's just going to take time" (for them to understand Paul, P.5, L.104). Reaching a mutual understanding had occurred despite Maria having a very difficult time: "It came to breaking point" (P.11, L.272). Donal had been presenting as very aggressive in school though this was not a feature of his behaviour at home. Maria interpreted this as Donal feeling "a bit lost ... it worked for him (when he was aggressive)" (P. 11, L.273). Maria was invited to a meeting in school where the board of management and a legal representative asked her to sign a document allowing staff in school to physically restrain Donal if necessary. Maria refused to do sign the document and the consequences entailed Maria being called to the school to bring Donal home whenever there was an issue with his behaviour. This situation lasted four years. These were very stressful encounters for Maria. Before enrolling Paul, Maria asked to see the school's policies and was told that she could not see

them until Paul was enrolled in the school and then she could only view them on school premises.

Maria was worried and frustrated by a number of issues in relation to school. She found staff intimidating and she experienced powerlessness and vulnerability there:

They can be quite intimidating (schools) and teachers from the school; there is that thing, you know, (they) have their degrees and they've been doing it for years, and .. even the way they would speak sometimes would come across quite intimidating, and .. that can be very hard to deal with when you're trying to .. essentially fight for your child (P.22, L.542).

Maria questioned the schools willingness and ability to cater for the needs of her children. She had experienced inappropriate treatment of Donal: "they'd bring you in for meetings, they'd have him in the room, and they would be just giving me all the negative things that he's done" (P.12, L.300). She wanted school to go well for her children but had no power or control to influence staff in school. She found it:

frustrating ... because as much as I'd like to have letters behind my name, and I don't have a degree in anything, but at the same time nobody knows him, and the issues that happen in school don't happen at all (at home) (P.5, L.108).

Maria felt that school staff would listen to professionals before they would listen to her despite that fact that "I know I'm not a professional but I know him" (P. 5, L.118). She felt that it was "very important for the parents and teachers to work together" (P.21, L.520) and despite the difficulties she'd had, she still wanted to work with school staff.

4.3.3 Maria's feelings about Paul starting school

Maria felt that the act of starting school would cause issues for any child whether they had special needs or not and felt that:

at that age, kids are all pretty much the same ... and they all have their little eccentricities and the things that they like and the things that they'll get locked into .. so the things that could be put in place like giving prior notice to what's going to happen and things like that – I think that would work for all kids across the board, to have them all understand (P.19, L.465).

Maria talked about what she felt about Paul starting school. Her feelings included hope, stress and worry. She was hopeful that because he was a year older, he would manage better: "I think he's ready" (P.18, L.430); "I'm happy about it because he's going to be that bit older" (P.18, L.433). She was going to meet with school staff "to make sure everything is in place" (P.8, L.189). Because of Paul's diagnosis, he would be entitled to **support**. Maria felt Paul was excited about the transition.

Maria had some worries because of her previous experience with Donal and with Paul starting the previous year and expected "issues" (P.9, L.204) to arise and "hiccups" (P.14, L.344). She was concerned that Paul's issues with toileting would cause problems for staff in school: "It leaves me a bit unnerved .. I'm just not sure what stance the school is going to take on it" (P.18, L. 436).

Maria worried that Paul might not get sufficient support from a special needs assistant as he "wouldn't necessarily be deemed as severe as others" (P.24, L.592). There was still some uncertainty about **the support** that Paul would receive which was concerning for Maria.

5 Hermeneutic cycle

I identified three overarching themes in Maria's transcript. These were "Maria's roles and relationships", "Understanding and being understood", and "Maria's experience and expectations of transition". I looked at how Maria's themes related to the research questions which were: What are the experiences of parents whose children with ASD are starting school? What goals and options do parents feel they have around their child's education? What kinds of feelings do parents have around their child starting school?

The overarching themes identified reflect Maria's day to day concerns as an individual and a mother and also deeper concerns about the nature of relationships and identity. In her transcript Maria made a number of references to herself, for example, that she was young and that she had to learn the hard way how to be an advocate for her children. She talked about her identity as a parent and how parents can be perceived by professionals, particularly the manner in which their expertise and experience can be dismissed and disregarded. In dealing with schools, it seemed that Maria's integrity as an individual and a mother was challenged; in the past, her youth and lack of insight into the way things worked had put her at a disadvantage when dealing with school personnel; being a parent meant she wasn't listened to and her advice and expertise wasn't taken on board. Maria had to build relationships in a careful way with school personnel so they would recognise her expertise as a parent and would listen to her.

It seems that in the case of Maria and her children, there is a cyclical nature to developing relationships, building communication and fostering understanding. Maria found it easier to approach people with whom she had a relationship, for example, staff in the preschool, and staff in school who now understood her "methods". This made it easier for her to communicate her needs and the needs of her children. When she could do this, she could foster understanding. She had learned to work with school through developing her own understanding of how the world worked by constantly meeting and communicating with them. Maria wanted to understand how things worked and she struggled with understanding the system (which didn't always work), she wanted to be understood herself, and she wanted her children to be understood.

Maria's experience and expectations of transition was a superordinate theme which reflected Maria's prior experience of both sons starting school. She had experience of Donal starting school in the past and had many dealings with school around Donal's issues which impacted on how she perceived school and staff in school. Paul had started the year before for a brief period so it was interesting that this was his second time starting school. His previous attempt had left a lasting impression which impacted on Maria's feelings about Paul

starting school. She worried about his toileting and how she would relate with staff.

In some ways, I felt there was a circular process at work in what Maria said, which is illustrated in the figure below.

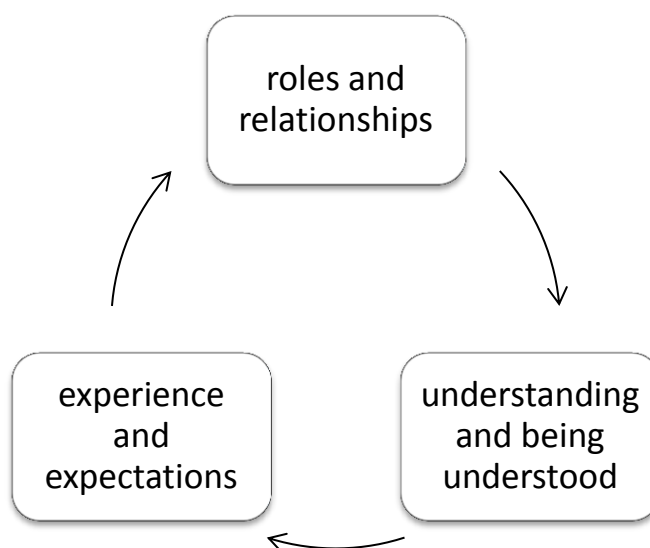


Figure 4 Circular process in Maria's overarching themes

This process might describe the importance of relationships and mutual respect and co-operation in fostering understanding which impacts on expectations and experience. Maria had learned through experience how to deal with professionals and staff in school. When she had relationships with staff she understood them and they understood her and she could communicate with them so everyone understood her children's needs. Her experience impacted on her expectations. When things went well, she was hopeful; when they didn't she was anxious.

From what Maria describes in her interview, other people don't always understand the perspectives of people with ASD. When everyone is working together to try and understand a child's needs, this is of great benefit to the child. In Maria's words:

With children on the spectrum, it's again one of the basics ... structure is what works, so you need it to flow between home, professionals, school,

if you need it – to flow. Obviously there will be slight differences cos they're different areas .. but if everybody is communicating, and everybody is working together, then the child has that security of knowing '.. everybody knows how I work (P.23, L.576).

Wing and Gould (1981) described a triad of impairments that is typical in the presentation of people with ASD. These include difficulties in social interaction, communication and imagination. It seemed to me that some of the issues with relationships and understanding that Maria described in her dealings with other people mirror these issues. Perhaps, difficulties in social interaction, communication and imagination are not limited to people with ASD but are present in systems which fail to promote development of relationships, which misunderstand the individual's attempts to communicate and where people have difficulty understanding other people's point of view or perspectives.

Baron-Cohen, Leslie & Frith (1985) proposed a Theory of Mind deficit to describe the difficulties people with ASD have in perspective-taking or understanding other people's feelings and intentions. In her story, Maria seemed to be struggling with systems and people who didn't understand her and seemed unable to take her perspective. She in turn, sometimes found it hard to understand their perspectives but was still trying.

From this interview I felt that fostering understanding and communication between parents and school staff would be important to help foster understanding of the children.

6 Reflexivity

For the purposes of reflexivity, I recorded my experiences of interviewing Maria afterwards. The interview took just over thirty five minutes and that seemed a short time to me. I was conscious of not wanting to probe too much into what Maria said in her interview. She offered concise, factual answers and also talked about how she felt about things. I felt that delving too deeply into her feelings would have been invasive and disrespectful, particularly in light of the negative experiences she had had in the past. I felt she candidly and honestly talked about some very difficult experiences.

In transcribing the interview, I attempted to record faithfully Maria's words, keeping as close to her intended meaning as possible. I noted that some meaning may have been lost in transcription such as that contained in her tone of voice and her non-verbal communication but this is a feature of IPA. IPA is about analysing the text. I learned how much I can mishear what someone says through the act of transcribing, for instance I was surprised how many times I had to replay the recording to get the full content of what was said. I felt that small mistakes would have an impact on interpretation. I felt some of my questions could have been leading and I endeavoured to be aware of this in subsequent interviews.

Following the interview, I sent a copy of the questions and the transcription to my supervisor so she could comment on whether this interview was sufficient. She felt this interview was sufficient to include in the study. Maria's interview made me think about issues that arise for individuals in systems and the challenges people can face when their experiences are outside of the mainstream experience. It made me think that despite the system's attempts to include parents at some level, education often takes place outside the family instead of the family being an integral part. The parent seems like onlookers who produce and present children to the school well-fed and clothed and ready to learn but whose role as natural educators is not fully acknowledged.

Appendix 16

Development of themes across the cases from individual themes

Individual Superordinate + subordinate themes

Tony and Catherine

Themes and subthemes	Superordinate themes
Trying to understand Chloe <ul style="list-style-type: none"> - Trying to understand ASD ✓ - Trying to understand Chloe's issues 	About Chloe
Restrictions on Chloe and family Feelings about other people's perceptions of Chloe	
Experiences of preschool Experiences of mainstream school Experiences of special class Support in finding a place	Trying to find the right place
Time wasted and missed opportunities Worry about the future Things will sort themselves out in time	Feelings about time and the future

Hannah

Themes and subthemes	Superordinate themes
Trying to get support from professionals <ul style="list-style-type: none"> - Support from SENO - Support from school - Support from special preschool and home tutor 	Getting support for James
Informal supports Making preparations for school Having the right information Finding the right school <ul style="list-style-type: none"> - Hannah's experience of schools - Trying to make the right choice - James's experience of school 	Preparing James for school
Hannah's internal struggle Hannah's struggle with the system Hannah's feelings about James starting school	Hannah's struggle with herself and the system
James Hannah's experience of ASD Hannah's feelings about stigma	About James

Maeve

Themes and subthemes	Superordinate themes
Different from other children Different from other parents	Maeve's feelings about difference
Impact of ASD on the family <ul style="list-style-type: none"> - Constraints on family life - Pressure on children - Stress for parents 	Impact of ASD on Maeve and the family
Impact of ASD on Maeve Maeve's understanding of ASD Wanting to be understood by others	Understanding and being understood

Being judged, being believed	
Maeve's feelings about sending her children to school	Maeve's feelings about school and sending her children to school
Maeve's experience of school and educational staff	
Trying to make the right choices	

Maria

Themes and subthemes	Superordinate themes
Relationships with other people <ul style="list-style-type: none"> - Because I'm just their mum - Professional v parent / education v experience - Conflict with other people - Building relationships Maria's depiction of herself and her children <ul style="list-style-type: none"> - Young mother, student, advocate - About Paul and Donal 	Maria's roles and relationships I'm young but I'm experienced
Trying to understand Paul Trying to understand the system <ul style="list-style-type: none"> - Maria's struggle to understand the system - Maria's feelings about conformity Trying to be understood <ul style="list-style-type: none"> - Maria trying to be heard - Paul trying to be heard 	
Maria's feelings about supports <ul style="list-style-type: none"> - Support for Paul in school - Support offered by Maria to the school - Changes in support for children with SEN Maria's experiences of preschool and school Maria's feelings about Paul starting school	Understanding and being understood Why can't they just understand?
	Maria's experience and expectations of transition

Olivia

Themes and subthemes	Superordinate themes
Feelings about Cormac's issues <ul style="list-style-type: none"> - Cormac's feelings about things - Preparing Cormac for the future and what Olivia wants for Cormac - Feelings about Cormac being different and wanting him to fit in 	About Cormac
Feelings about Cormac starting school Experience of Cormac's diagnosis	
Take the initiative or wait for services	Passage of Time

Changes over time	Olivia's experience of services, supports and the system
Uncertainty about the future	
Impact of timing	
Dealing with professionals and the system	
<ul style="list-style-type: none"> - Understanding versus frustration - Being heard and being understood - Fighting for your child 	
Olivia's experience of Cormac going to preschool	
Informal supports	

Quotes to support development of themes across the cases
<p>I think they'd need to <i>believe</i>, believe what we're telling them</p> <p><i>Fighting for my child</i></p> <p>Tony: and then when they (professionals) start telling you 'Oh, she should be doing this; she should be doing that by now', you're just thinking 'Why? Why should she?' (P.44, L.1539).</p> <p>Catherine: Yeah! You nearly get offended; you nearly get annoyed (P.44, L.1542).</p> <p>Olivia: You're like fighting .. it's like fighting for your rights kind of thing (P.19, L.460); You have to push ... and get a bit of a thick skin as much as you mightn't be that person .. it's like a different persona you have to almost be .. to fight your corner (P.26, L.639).</p> <p>Maria: I find the schools tend to nearly take offences to that (being asked why something is going wrong), almost like I'm trying to shift the blame onto them, instead of understanding: I'm not trying to get anyone into trouble here – I'm trying to find out exactly what's going wrong so we can fix the problem (P.22, L.529).</p> <p>Hannah: I probably could have fought to get him an SNA maybe, but I think maybe in the long run, it's going to be .. all well; I hope it works out, do you know, it's a- it's really, it's on my head ... it's – it's still at the back of my mind I didn't - did I fight h- hard enough for him? (P.12, L.357).</p> <p>Maeve: It was awful. I was bawling crying (when the school principal questioned her older son's diagnosis) (P.21, L.521).</p> <p><i>Wanting to be heard and believed</i></p>

Catherine: They'd think that she doesn't understand what you mean but we know that she does, she's just being impatient and she's just being like any other kid would be ... other people looking at that ... would look at her and say 'she doesn't understand that' but we know that she does (P.27, L.915).

Olivia: when we spoke to the preschool .. they hear what you're saying but they don't take it on board as much as a professional and I always found from day one, if you could bring someone in then they tend to listen that bit more ... they listen to professionals more definitely (P.8, L.195).

Maeve: I think they'd need to believe, believe what we're telling them, not look at us as if that we're making this up on them. They make us feel as if we're bad parents, do you know, and we could be the worst parents in the world and we still wouldn't be going through this (P.33, L.819).

Maria: It's whether or not they'll hear me or not; that's what worries me (about school staff) (P.18, L.442).

Hannah: Even in our own families, people say .. he is very high functioning ... that 'there's not a thing wrong with him', you know; I'm sorry, I never asked for this ... It's not something I want and I suppose the fact that we don't tell people either that you'd think they'd understand, you know, that you know, we're just trying to understand him and get the best - the best out of him and the best for him, you know? But there's still a fair bit of stigma, even though it's a lot more common now, it's still ... and the- there's always that thing are they doing it for the benefits ...? (P.13, L.388).

Experience of ASD: It's a very labelling thing

Is this the way our life is going to be now?

- Impact of timing of the diagnosis

Catherine: I think the fact that she didn't get diagnosed until she was four and a half years old hindered her for a lot of placements ... you've missed all the places, there's just not enough places (P.40, L.1417).

Tony: I think that the struggle that we had in finding places for her was because ... the diagnosis of the assessment was coming close to the school time (P.39, L.1394).

Hannah: When he was maybe about .. just turned three when we found out so luckily, my – I have a neighbour who has a son on the spectrum, she told me about the preschool in <town> and actually there was nothing else around so had I not known about that I would never have .. known to put him there and he got a year there and then we had to fight to get the second year and that gave me two years then to decide where to put him and at that stage we knew he was well able for .. mainstream and it was just a matter of finding the right school (P.1, L.8).

Olivia: for us it's been a huge learning .. thing, like, and just because he is diagnosed so early we're lucky that we can work on all these things (P.42, L.1004).

- Initial reaction to the diagnosis

Tony: and that's the way we were thinking for a year and a half and then after that, for someone to say 'yeah, there's a diagnosis of autism there', it's ... you can't mentally prepare yourself for that because you .. you won't see it in them, you won't, you'll never see anything wrong with them (P.43, L.1532).

Catherine: When they actually tell you ... it still comes as a bit of a blow ... it's like 'Oh God'; it does come as a bit of a – a blow because you're like: 'What am I going to do?' You kind of see things slipping away and little things ... you know, it's hard to explain because I think you think the worst whereas because we knew nothing about it, you know, and they just started talking about special classes and ... that comes as a bit of a sh- shock going 'Oh my God' ... you start thinking all these horrible things that will happen which might never happen (P.43, L.1505).

Olivia: and it was just very emotional; for a month any time I was thinking of

stuff I felt like crying, do you know, because I was going ... just in the long run: 'Is this the way our life is going to be now? That we're kind of going to schools in <town> or, or do we have to look at moving? Do you know, there's a bigger picture in all of that then (P.11, L.255).

Maeve: A lot of parents don't like their children being labelled but we couldn't wait (P.23, L.570).

Meaning of ASD

- Construction of ASD and trying to understand how it manifests in my child

Tony: When it's your child, all's you see, especially your first as well, all's you see is .. positive; you don't see anything bad about them at all so that whole year and a half while we were waiting (for the diagnostic assessment) ... we were just going: 'ah, there's nothing wrong, there's nothing wrong, she's perfect' (P.43, L.1517).

Catherine: I knew coming up on three that maybe she should be talking more ... I suppose you're kind of thinking to yourself: 'should we have called someone in when she was two?' .. but you don't know, you see, it's your first child, you don't know when they should be doing this, when they should be doing that (P.40, L.1417).

Maeve: Peter and David are two very different children with very different needs (P.4, L.87); That's one of the main things the school needs to realise, just how severe that running is .. that he will climb out of anything. He's climbed out of the sitting room window and run up the street naked many a time (P.29, L.721).

Olivia: He'd be full of chat ... but then you'd see, like social, he'd be looking away and like, speech-wise, he's always been grand ... but then his communication wouldn't be great which can fool people; and it fooled us for a long time as well (P.1, L.4).

Maria: different things that I'll have to bear in mind for Paul that someone whose

child isn't on the spectrum wouldn't have to bear in mind (P. 19, L.462).

Hannah: It's just an awful worry that they won't .. you know maintain friendships and build on them when you get that bit older. You know, you'd hate for them to be a loner or just .. am, you know especially when they're into technology, they just get *lost* in it (P.22, L.654)

Tony: From what we read and stuff and what people have told us that some ... children with autism, that they don't like physical contact, where she's the opposite (P.20, L.649).

Maeve: Sometimes I wonder should we all be a bit more autistic, do you know, and because they (people with ASD) just take people as they come, whereas, do you know, the mainstream, i – it's just such a worry and it's a horrible feeling dropping them there every day (P.35, L.867).

Olivia: It's like kids with ASD speak the truth it's the rest of us *don't* (laughs). The rest of us are saying the niceties for the sake of it" (P.56, L.1451).

- Other people's perceptions of ASD

Hannah: because he's so f- high functioning I really want him to fit in, you know, so we made the decision anyway, we told our neighbours, really neighbours and we'd have family; no one else really knows because I ... I don't want the stigma of they – they won't invite him to playdates now or he could be excluded (P.13, L.374).

Olivia: when you get a diagnosis as well it's a very *labelling* thing and I've done it myself or "oh, that child has autism" or and then ... you don't realise the levels of it and people are quick then to kind of .. not be dismissive or eh "oh poor old <Cormac>" ... I don't want him to be that .. and we've deliberately not told *too* many people around here because the village is so small that, do you know, it's just talk, it's just idle talk that does the child no good or it's not their business either (P.54, L.1412).

Maeve: I just think there's so much pressure on society now that everyone has to be the same ... and they're not the same (P.36, L.881).

Catherine: And then she'll scream and then you get people looking over at her and I get hyper and I get mad (P.3, L.102).

Tony: I think people have underestimated her a lot in the past ... they haven't seen her full potential there (ASD service) ... there's so many things that she can say and that she knows how to do and stuff but she just ... it's like she can't be bothered (P.18, L.580).

Maria: People tend to forget that they (children with ASD) don't understand (social situations) (P. 6, L.142).

Preparing for school and preparing for the future

Finding the right place

Olivia: We went from thinking he just had sensory processing disorder then to going: 'do we have to send him to a special school?' Within a week ... We didn't even have time for it to sit to go 'right' (P.11, L.255).

Hannah: So I think this is perfect for him, you know, the small school, it's just what he needs. You can even see in everything – he's just so confident now since he's starting and he's talking with his friends (P.1, L.21).

Maeve: Why don't the government just do that? Why can't they have a school just for high functioning special needs children – it would make lives a lot easier for teachers, parents and children. Everyone would be happy (P.35, L.876)

Tony: I suppose we were thinking initially with mainstream is kind of 'throw her in the deep end .. she'll struggle, and over time, she'll catch up' but then we've kind of realised that that's .. not realistic (P.17, L.552)

Maria: They (school staff) understand me now and so I know it's just going to

take time (for them to understand Paul, P.5, L.104).

Catherine: you're panicking over that going "How is she going to cope in the classroom, when she's running around them and you would just have everyone else affected by her ...disturbing the place?" ...it wouldn't be fair on her and I don't think she'd be getting what she needs (P.11, L.368)

What I want for my child

Hannah: It's really his social skills that I'm kind of worried about, do you know that I really want him just to fit in kind of more. And sometimes, I think am I just conscious of it, that I can see – do you know, when he's running around and his hands are spinning? Am, or you know like ... maybe other parents don't notice, I don't know. Maybe we're just paranoid. But I really just want him to fit in another little bit, do you know ... he's so kind of .. like, he kind of *is* like an old man sometimes, you know that? And I'd be just like 'Please God, let him just get through school, go to college' and you know, not be worried. You know (laughs) I really hope he will. (P.21, L.622).

Catherine: I've met the principal. He's lovely ... so friendly ... I came away just feeling really happy, saying "Please, please God, get her a place in here!" because even the couple of teachers that were going around, they were all so friendly ... you just got a really nice feeling out there which is .. what you want (P.14, L.466).

Tony: Just that she's happy there (P.32, L.1058).

Maeve: Now we've got choices with David, and hopefully we're making the right ones this time (P.17, L.402).

Maria: (If Paul) has the supports he needs, he'll be fine ... it's whether or not he's going to get that" (P.18, L.449).

Feelings about the future

Olivia: I think as time goes on anyway you realise .. I think the first few years it's

all so much. As time goes on, do you know, it's just like, do you know we can deal with it ... and like that, things arise just day to day anyway ... it's like anything, if you think of the bigger picture, it's like 'Oh Jesus ..' (laughs): break it down, it's all right (P.56, L.1471).

Tony: She's not going to be ... like that (noise sensitive) for her entire life. She's obviously going to find a way to cope with it (P.5, L.169).

Catherine: All of a sudden in the last couple of months – anything can set her off ... we're getting to the point where we nearly can't take her anywhere (P.3, L.96).

Hannah: It's just an awful worry that they won't .. you know maintain friendships and build on them when you get that bit older. You know, you'd hate for them to be a loner or just .. am, you know especially when they're into technology, they just get *lost* in it (P.22, L.654).

Maria: If Paul understands what's happening and he knows there are people he can go to that he trusts... he will settle, but if he doesn't have that security, it will get out of control (P.18, L.444).